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Delivering Universal Health Care to People with Major Limb Loss or Damage in Low and Middle Income Countries

A Complex Intervention in Uganda

Louise Ackers · Jonathan Huck · Laurence Kenney · Allan Ndawula · Jackson Murungi

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We dedicate this book to our respondents and all those people living in Uganda with physical disabilities in the hopes that a brighter future lies ahead.

Foreword

I am delighted to see the outcomes of the health partnership interventions reported on in this book and the evidence base this has generated. In 2023, the Ugandan Ministry of Health started an ambitious planning process to develop and implement the first Ugandan National Rehabilitation and Assistive Technology Strategic Plan. This represented an immediate response to the World Health Organisation's Rehabilitation 2030 Call for Action. The initiatives supported by the partnership between Fort Portal Regional Referral Hospital, Knowledge For Change and the University of Salford, UK respond directly to 3 Key Actions of the Strategic Plan. Namely, enhancing information systems, building research capacity and expanding the availability of robust evidence and establishing and strengthening partnerships between low, middle and high income countries. Complementing multi-stakeholder, sectoral collaboration and partnerships with practitioners, this research has actively engaged Ugandan early career researchers and people with disabilities.

The book emphasises the inefficiencies and damaging impacts associated with poorly aligned overseas contributions, particularly the development of parallel systems. Through its projects, Knowledge For Change works closely with the Ministry of Health to support the delivery of Universal Health Coverage to benefit all the Ugandan people.

The work represented here contributes a significant and unique evidence-base to support our future Rehabilitation and Assistive Technology service planning and implementation processes.

Kampala, Uganda

Andrew Mubangizi
Assistant Commissioner
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Claire Horder as long term K4C volunteer actively supported the work on the ground and those aspects of the work closely linked to her NHS-England funded doctoral research on virtual volunteering. Miriam Nantamu supported empirical work in Uganda as part of her post-doctoral research. Timothy Isingoma and Richard Isingoma both played a key role in interviewing amputees as expert users. Timothy is also one of the orthopaedic technology team at Fort Portal Regional Referral Hospital lead by Tom Baguma responsible for providing rehabilitation services. Kirsty Watkinson and Simona Ackers-Johnson provided support with the GPS mapping. Oliver Williams played an active role as one of K4C's professional volunteers in supporting the accountability mechanisms and exploring potential suppliers during a 4 month stay in Uganda in 2022.

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Our special thanks go to the Director of FPRRH, Alex Adaku and the Hospital's Senior Administrators Maggie Batamuleza and Michael Odur for their constant support and active engagement. Their willingness to support a unique Social Enterprise approach demonstrates the potential for a sustainable alternative to donorism.

We have greatly valued the opportunity to contribute to the Ugandan National Rehabilitation and Assistive Strategic Planning meetings organised by Assistant Commissioner Andrew Mubangizi and welcomed his visits to the Fort Portal Workshop and active contributions to project review and development.

Contents

Acronyms

ADF	Allied Democratic Forces
APL	Assistive Products List
ATScale	Global Partnership for Assistive Technology
CBO	Community Business Organisation
CBR	Community-Based Rehabilitation
DRC	Democratic Republic of Congo
EMS	Emergency Medical Services
EPSRC	Engineering and Physical Sciences Research Council
F4P	Fit For Purpose
FPRRH	Fort Portal Regional Referral Hospital
ICRC	International Committee of the Red Cross
IPV	Intimate Partner Violence
IPPV	Intimate Partner Physical Violence
K4C	Knowledge for Change
LMIC	Low and Middle Income Countries
LNOB	Leave No One Behind
MLL	Major Limb Loss
MOU	Memorandum of Understanding
MRC	Medical Research Council
NDA	National Drug Authority
NGO	Non-Governmental Organisation
NMS	National Medical Stores
ODA	Overseas Development Assistance
PNFP	Private Not for Profit
POP	Plaster of Paris
PPP	Public Private Partnership

PPP/H	Public Private Partnership in Health
RRH	Regional Referral Hospital
RTA	Road Traffic Accident
SDGs	Sustainable Development Goals
SSA	Sub-Saharan Africa
TBS	Traditional Bone Setting
THET	Tropical Health and Education Trust
UDHS	Uganda Demographic and Health Survey
UGS	Ugandan Shillings
UHC	Universal Health Coverage
UMoH	Ugandan Ministry of Health
WHO	World Health Organisation

List of Figures

List of Tables

CHAPTER 1

Why Rehabilitation?

Abstract This chapter provides some context on rehabilitation services for people with major limb loss in Uganda. It outlines the prevalence of limb loss and the legacy that humanitarian approaches to overseas development assistance have had on rehabilitation services. It then sets the global policy context that is stimulating and framing the development of the first Ugandan National Rehabilitation and Assistive Technology Strategic Plan. The chapter then introduces the Fit-4-Purpose complex intervention project and outlines the structure of the book.

Keywords Assistive devices · Fit-4-Purpose · Low and middle income country · Major limb loss · Prosthetics · Rehabilitation services · Universal Health Coverage

Introduction

Limb loss in a low resource setting is not only a personal tragedy. It also undermines a person's socioeconomic participation driving them and those who depend upon them into absolute poverty. The absence of effective social protection and/or health insurance systems further compounds this, with particular impacts on women and girls (Cote, 2021). The lack of preventive services to reduce the prevalence of limb

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loss, notably from non-communicable disease and intentional and unintentional injury, coupled with almost non-existent rehabilitation systems has multiplier effects for health systems and economies, undermining productivity (WHO, 2016). According to a recent report an estimated 65 million people live with limb amputations globally and about 1.5 million undergo amputations annually; 'Most amputees need access to prosthetic services and this need is expected to double by 2050, particularly in Low and Middle Income Countries' (Liao et al., 2020).

At the present time the Ministry of Health in Uganda does not fund equipment or materials for prosthetic manufacture across its network of 13 regional orthopaedic workshops. To the extent that services are available, they are 100% dependent on external finance largely from overseas 'donors' motivated and shaped by humanitarian/emergency approaches. The distribution and quality of physical rehabilitation[1] services in Uganda reflects the location and history of civil war, conflict and refugee displacement. Harkins et al. point to the need for a shift towards sustainability as the 'long-term legacy of many modern conflicts becomes an impediment to service provision' (2013: 358). Unfortunately, in the transition from conflict to a context where road traffic accidents, domestic violence and diabetes form the major and more distributed causes of limb loss and damage, this legacy thrives. One of the inevitable limitations of donorism is the geographical 'patchiness' of services and their episodic (temporal) quality. The association of physical rehabilitation with conflict has tended to marginalise this area of healthcare from dominant and visible priorities; in post-conflict contexts physical rehabilitation (and those people requiring services) have been rather 'left behind'.

For many years capacity-building in global health has been dominated by a narrowly medicalised 'treatment' agenda emphasising infectious disease, emergency medicine and maternal and child health. As Bouchard et al. note, 'disability globally has surprisingly not been a global health issue' (2012: 2). In 2017, the World Health Organisation launched its 'Rehabilitation 2030 Call for Action' (Table 1.1).

[1] We use the term 'physical rehabilitation' in the book as a collective term to describe services for people with major limb loss. We have avoided the term prosthetics as it is associated with quite specific approaches and professional roles in high income countries.

Table 1.1 Rehabilitation 2030 Call for Action (WHO, 2017)

There is a substantial and ever-increasing unmet need for rehabilitation worldwide, which is particularly profound in low- and middle-income countries. Rising prevalence of noncommunicable diseases, the ageing population, and improved access to emergency, trauma and medical care correspond with a growing demand for rehabilitation services
In many parts of the world, however, the capacity to provide rehabilitation is limited or non-existent
With its objective of optimizing functioning, rehabilitation supports those with health conditions to remain as independent as possible, to participate in education, to be economically productive, and fulfil meaningful life roles. As such, the availability of accessible and affordable rehabilitation plays a fundamental role in achieving Sustainable Development Goal (SDG) 3, "Ensure healthy lives and promote well-being for all at all ages"

The Call for Action identifies 10 priority areas including:

1. Leadership and political support
2. Strengthening rehabilitation planning
3. Improving integration and strengthening intersectoral links
4. Incorporation of rehabilitation in Universal Health Coverage
5. Building comprehensive rehabilitation service delivery models to achieve equitable access
6. Developing a multidisciplinary rehabilitation workforce
7. Expanding financing for rehabilitation
8. Enhancing information systems
9. Building research capacity and expanding the availability of robust evidence
10. Establishing and strengthening partnerships between low, middle and high income countries.

Priority 2 (strengthening rehabilitation planning) is being taken forward by the Ugandan Ministry of Health (UMoH) in an active strategic planning process. In direct response to the WHO Call to Action, the Ministry of Health (UMoH) aligned its Strategic Planning process[2] with its commitment to the UN Convention on the Rights of Persons with

[2] This process has been actively supported by USAID via the ReLAB-HS program led by Sam Tukei Ojulo.

Disabilities and its implementation through the Persons with Disabilities Act (2020). In February 2022, the UMoH hosted the Second Global Disability Summit. The report on this summit characterises Uganda's orthopaedic workshops as 'non-functional for assistive technology/devices' and includes a commitment to 'equip 40% of the orthopaedic workshops across the country to facilitate quality production by 2024' (UMoH, 2022: 29).[3] February 2024 saw the launch of Uganda's first National Rehabilitation and Assistive Technology Strategic Plan (2024/5–2029/30). The Strategic Plan grasps the opportunity to embrace not only post-injury physical rehabilitation but also disability prevention in the context of fast-changing demographics and the associated rise in the same long-term health conditions that threaten public health systems in high income countries. It also recognises the potential cost-benefits associated with preventive and supportive intervention both in terms of reducing hospitalisation and associated costs but also promoting individual livelihoods, independence and wider economic productivity. Echoing the Disability Summit report, the Strategic Plan openly acknowledges that the need for rehabilitation is 'large and growing yet current rehabilitation needs are largely unmet' (p. 3). Access to assistive devices is reported as minimal with only 4% Ugandans with functional limitations using such products. Among those who do use assistive devices, 'only 15% obtain products from government, whilst 63% pay for them personally or rely on family and friends for financial support. Nearly 90% individuals with functional limitations report being unable to afford these products' (p. 4). The Strategic Plan identifies a number of Key Challenges (Table 1.2).

The UMoH argues that the ability to respond to these challenges is made more complex by 'heavy reliance on inconsistent donor support [which] hinders sustained provision creating problems of service coordination and continuity' (p. 6). It is in this context and with these challenges in mind that the book presents evidence from a series of research studies on users' experiences of major limb loss and accessing health services in Uganda and on attempts to create and evaluate novel responses.

[3] To date no progress has been made to equip workshops.

Table 1.2 National Rehabilitation and Assistive Technology Strategic Plan (Ugandan Ministry of Health 2024/5–2029/30)

Key Challenges:
Lack of **resource allocation** to rehabilitation
Absence of **accountability** mechanisms
Poor **coordination** and disjointed planning
Inadequate **infrastructure** and essential **supplies**
Underutilisation of rehabilitation **professionals**[4]
Limited **access to products** particularly mobility aids and lower limb prosthetics
Absence of robust **procurement** and **supply chain** infrastructure

The Fit-4-Purpose Intervention

This book draws on on-going complex intervention research taking place through an established Health Partnership linking a UK and Ugandan registered NGO (Knowledge For Change or K4C[5]) and Fort Portal Regional Referral Hospital (FPRRH) in Western Uganda which works to address the needs of people who have suffered limb loss in Uganda[6] and the challenges they face in accessing prosthetic services.

With support from the UK's, National Institute for Health Research with the Engineering and Physics Research Council,[7] the Foreign and Commonwealth Development Office with the Medical Research Council[8] and the Tropical Health and Education Trust,[9] this book reports on this work. We have used the concept of Fit-For-Purpose to describe this area of work as we feel the concept captures well the importance

[4] The report notes that only 198 of over 1000 health professionals accredited by the Uganda Allied Health Professions Council in 2022 were employed in public service (p. 6).

[5] UK Charity Commission Reference 1146911: NGO Board, Uganda 3592.

[6] K4C supports a South-South knowledge translation initiative with a sister health partnership in Zanzibar and plans to scale-out the intervention in Mnazi Moja hospital.

[7] 'Fit-for-purpose, affordable body-powered prostheses', EP/RO13985/1.

[8] 'Promoting Universal Health Coverage for Amputees through Social Enterprise and Engineering Innovation', MR/V015214/1.

[9] VB4. In November 2024 THET was renamed the Global Health Partnerships reflecting a revised mission: https://www.thet.org/tropical-health-and-education-trust-thet-becomes-global-health-partnerships/.

of co-developing the evidence-base for policies that are deeply contextualized and recognise the significant challenges facing health systems. The Cambridge dictionary defines F4P as, 'suitable and good enough to do what it is intended to do'.[10] This nicely echoes the principle of 'good enough parenting' challenging the elusive strive for perfection and acknowledging parenting as ultimately a process of reflexive learning from mistakes and trade-offs (Winnicott, 1973).

In the first instance, in 2018, a team led by Professor Kenney secured funding to address the specific needs of upper limb amputees. The 'Fit-4-Purpose' project focused on the co-design of mechanical upper limb prosthetic devices, including user-adjustable upper limb sockets and prosthetic hands. The goal was to move towards local manufacture of novel co-designed devices and build an understanding of how prosthetic services fit within the wider health system to support this process. It emerged very early on that access to materials and supply chains would form a major barrier to bringing any design innovation 'to market'—and to users. Subsequent funding from the Medical Research Council created the opportunity to focus in more detail on the supply chain dynamics shaping access to and the costs of prosthetics manufacture. Within the same project we took advantage of industry's emerging focus on prosthetics suitable for use in LMICs, to test the deployment of a novel upper limb prosthesis, the Koalaa ALX system.

This represents a direct response to the WHO's commitment to find way ways of harnessing health financing practices to avoid 'Catastrophic Out Of Pocket Expenditures' (World Health Organisation, 2017). With a primary focus on research capacity-strengthening and the generation of robust evidence (Priority Area 9) the book is designed to inform and support the planning of physical rehabilitation services.

There are very few empirical studies of physical rehabilitation services in LMICs. Most of the studies that do exist draw on literature reviews and concur, with Harkins et al. (2013) that there is a 'lack of quality available research' (p. 353). One of the consequences of current research approaches is the tendency to gloss over the significant diversity of welfare systems within the 'LMIC' envelope. Harkins et al. acknowledge this weakness and conclude that the level of complexity influencing service development requires that physical rehabilitation services are 'tailored to

[10] FIT FOR PURPOSE | English meaning—Cambridge Dictionary (https://dictionary.cambridge.org/dictionary/english/fit-for-purpose).

address the needs of individual countries' (p. 353). We have taken a longitudinal, multi-method, action-research approach designed to capture emerging outcomes and causal dynamics.[11] Building on a previous paper (Mulindwa et al., 2023) the book draws on a complex data set at the centre of which are 60 qualitative interviews with people who have suffered major limb loss (MLL). The sample included people receiving services at the orthopaedic workshop[12] at Fort Portal Regional Referral Hospital (FPRRH) between the years of 2021 and 2024. All of the sample benefitted from free public services provided as part of the planned F4P Health Partnership intervention. In that respect they are an unusual sample, and their experiences will not reflect wider experiences of rehabilitation services across Uganda. The interviews encouraged respondents to trace their journeys from the original cause of their subsequent amputation and track their health seeking behaviour and service experience. The data from this sample is complemented with a range of other sources. These include interviews with orthopaedic technologists (20), site visits to 4 orthopaedic workshops combined with participant-observation in one workshop over a 7-year period and interviews with researchers (16), stakeholders (15) and staff involved in distribution and procurement (16). This primary data collection sits alongside the development of a continuous audit[13] of patient characteristics and materials consumption in the Fort Portal Regional Workshop. The Fit 4 Purpose study was particularly interested in the experiences and needs of upper limb amputees and gain their perspectives on the range of products currently available. In order to ensure we captured this quite unique sample the study team adopted a different sampling strategy identifying upper limb amputees who were registered with an Orthopaedic Clinic in Kampala. This yielded a sample of interview with 17 upper limb amputees. As one of the work packages in the MRC-funded project (MR/V015214/1), 8 amputees, plus 2 'limb buddies' were recruited via a range of different routes, and fitted

[11] Makerere Ethics Approval SBS-2022-205.

[12] To the extent that public physical rehabilitation services currently exist in Uganda they are based in what the UMoH call orthopaedic workshops staffed by orthopaedic technologists and technicians.

[13] The audit process has been part of data collection but also a critical component of the intervention.

with the Koalaa devices.[14] Some of the interviews with the 8 participants who tested the Koalaa device are discussed in Chapter 7.

The research has actively engaged early career researchers in Uganda including co-researching health workers, some with lived experience of limb loss or damage. A co-researching 'limb-buddy' approach was used in all the interviews involving an upper limb and lower limb prosthetic user either working on their own or alongside another member of the research team. The qualitative interviews took place in the user's language of choice. Where this was Rutoro (the dominant local language in the Fort Portal region) both limb buddies were able to interview in Rutoro and subsequently support the translation and transcription process. Qualitative data, including interview transcripts and notes from continuous participant observation and project meetings, were transcribed and analysed within an NVivo12 project.

The data familiarisation phase was undertaken in the field working alongside Ugandan co-researchers. This enabled us to check some of the specifics (dates and facilities etc.) and ask further questions about cases where necessary. Initial code generation took place in this co-researching context initially on paper then in a trial NVivo project. Braun and Clarke (2019) advocate a reflexive approach to thematic analysis reflecting on their earlier work and the tendency of the many thousands of researchers who cite it to treat it as a prescription for a 'rigid, linear series of stages' (p. 592) or 'baking recipe'. We very much support their advocacy of a more 'fully' qualitative and creative approach focused on the generation of carefully contextualised, positioned and situated meaning rather than the pursuit of 'truth'. An iterative (and time-consuming) process of reading; re-reading, discussing and trying-out themes took place to gradually build the scaffolding for data analysis. The process of achieving a shared understanding of initial themes generated inductively from the narratives inevitably lead to the overwhelming 'messiness' that necessarily characterises qualitative research. Cook's work on the 'purpose of mess in action research' throws light on this experience describing 'mess' as 'new opportunities for seeing and knowing' rather than failure or poor quality research. Complex intervention research is inherently 'messy'. Whilst researchers often openly discuss mess during the research process this discussion rarely enters published work which is often presented in

[14] This is discussed in more detail in Chapter 7.

a sanitised form concealing some of the uncertainties, contestations and apparent 'failures' negotiated along the research journey. Cook describes the process of generating meaning from 'mess' as 'co-labouring' and this describes well our experiences of engaging with respondents' narratives. This process took place through co-present working in situ in Uganda. Mindful of the environmental impacts of flying in partnership working we believe that co-presence at this stage in the process was crucial to achieve genuinely shared understanding and theorisation.

As themes emerged, they were continually reviewed and redefined to shape a meaningful structure. At this point a new NVivo12 project was opened for coding which took place in Uganda working alongside Ugandan researchers. Writing is an integral part of on-going reflexive data analysis and reflections on the data led to continuous review of the themes and their relationships to each other. The authorship team has included more experienced UK-based researchers working alongside early career researchers from the Ugandan team who have been most closely involved in the research.

The Book

Our approach to analysing the life history interviews has been influenced by our previous experience of using the '3-Delays' approach initially developed to capture, holistically, the underlying causes of maternal mortality (Ackers et al., 2016; Thaddeus & Maine, 1991). The Model characterises Type 1 delays as linked to health awareness and health seeking behaviours. Type 2 delays are concerned with physically accessing services and Type 3, to the Quality of Care on arrival. In simple terms the Model assumes a linear process which rarely maps onto patient experiences in Uganda. Pickering et al. (2022) applied the 3-Delays model to their analysis of patient and caregiver's experiences of accessing Emergency Departments in Uganda. The 3-Delays model encourages us to track patient journeys back to root causes or triggering events. It is perhaps unsurprising in a study concerned with major limb loss to find that, in many cases, the triggering event was some form of serious injury. As such respondents' first engagement with the health system was in an emergency context. Whilst this arguably falls outside our focus on physical rehabilitation services our initial analysis of the interviews made us realise the profound impact this experience had on subsequent rehabilitation

journeys, particularly as a result of loss of livelihood and catastrophic out-of-pocket-expenses. Respondents' experiences of accessing emergency care are discussed in Chapter 2.

Whilst Pickering's focus on emergency care will, in many cases, start with a key trigger (an accident) this is not always the case and, as we shall see in Chapter 3, for many of our respondents limb loss took place after a long period of deteriorating illness. Here Type 1 delays linked to awareness and health seeking played a very major role in patient outcomes. Chapter 3 focuses on those cases where undiagnosed non-communicable diseases or chronic wounds eventually led to amputation.

Having detailed some of the factors leading to limb loss, Chapter 4 turns to examine subsequent health seeking behaviour and respondents' experiences of physical rehabilitation services. It illustrates the consequences of the overwhelming reliance on international NGOs and donorism referred to in the UMoH Strategic Plan and the spatial and temporal legacy of humanitarian approaches. This legacy inevitably leaves many people 'behind' and reliant on largely unfunded and poorly distributed public services. Chapter 5 explores the experiences of those 'left behind' and the challenges they have faced in trying to—or deciding not to—access physical rehabilitation services. Chapter 5 documents the process by which orthopaedic technologists in the Ugandan public workshops attempt to provide services to people with MLL in the absence of any funding for devices or materials and a ban on charging patients. This sets the scene for a discussion, in Chapter 6, about the impacts of the current under-funded and ODA-dependent rehabilitation system on supply chains and the costs of prosthetic device manufacture. We draw attention to the materials and componentry involved in manufacturing prosthetic devices and how these are currently accessed from international markets. We go on to examine the service landscape and processes a patient will go through in an attempt to access services, and how this impacts demand for materials and supply chains. We outline the evolution and impacts of a social enterprise intervention co-designed through active Health Partnership documenting the potential for social enterprise to support both a growth in free public services and drive down unit costs.

The WHO Assistive Devices List makes no mention of upper limb prosthetic devices. This absence is echoed in the Ugandan Strategic Plan. Chapter 7 reports on methods used in a study conducted as part of the MRC project with a specific focus on the needs of people with upper limb

loss. In particular, it outlines a novel approach to capturing the impact of prosthetic devices on user behaviour.

Finally, Chapter 8 summarises some of the key learning from the F4P complex intervention process of direct relevance to the implementation of Uganda's First National Rehabilitation and Assistive Technology Strategic Plan. Drawing on the evidence it presents makes some policy recommendations aligned with the WHO Call to Action and the UMoH planning process.

CHAPTER 2

Patients' Journeys to Amputation (1): Emergency Care Services

Abstract This chapter presents findings from interviews with respondents on their experiences of accessing emergency care services in Uganda following some form of trauma. It discusses the status of emergency care services in Uganda and some of the main causes of accidents including Road Traffic Accidents and Inter-personal Violence. Key concerns around the delays in accessing care and the catastrophic costs involved at this stage in patient journeys set the context for our subsequent findings on rehabilitation processes.

Keywords Catastrophic out of pocket costs · Emergency care · Delays · Interpersonal violence · Road traffic accidents

Characterising Accidents and Violence: Our Sample

All 60 respondents interviewed as part of the main study had accessed services at the public Orthopaedic Workshop at FPRRH. Our primary interest when designing the interview questions was in their experiences of seeking *physical rehabilitation* services. We hadn't anticipated the impact that their previous experience of health services and, more specifically their journey to amputation, would have on subsequent decisions.

L. Ackers et al., *Delivering Universal Health Care to People with Major Limb Loss or Damage in Low and Middle Income Countries*,
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Fortunately, following a 'life-course' approach to qualitative interviewing with its emphasis on understanding the wider context behind human behaviours and, more generally, showing an interest in subjects to build rapport meant that we inevitably tracked respondents' histories. As we began to analyse the interviews, we realised the importance of these pre-amputation journeys and the critical role they played in shaping attitudes towards and access to physical rehabilitation. The data collected on the cause of limb loss amongst our sample found that in 30 cases (50%) the amputation was triggered by some form of injury or condition requiring emergency medical services (EMS). In the first instance it is important to note that only 1 of our sample was a conflict injury sustained as a child many years ago on the border with the DRC. The majority of cases involved an injury on the road or roadside (a Road Traffic Accident or RTA). Motorcycle accidents were more common than car/truck accidents, but a substantial number of cases involved injuries to pedestrians or cyclists (Table 2.1).

Many of the RTAs (and other injuries) also took place in the course of the patient's employment drawing attention to the lack of corporate responsibility or insurance cover. The cases also illustrate the role that inter-personal violence plays in limb loss and damage in LMIC settings. The interviews reveal the long and complex journeys many patients made prior to amputation spanning public, private and not-for-profit facilities. What is conspicuous through its complete absence is any reference to public ambulance services either in response to the initial accident or in referrals. Perhaps the most shocking findings relate to the costs associated

Table 2.1 Type of medical emergency triggering amputation

Medical emergency type	
RTA motor vehicle	4
RTA motorcycle	8
RTA pedestrian	7
Cyclist	1
Total RTAs = 20	
Occupational accident (not RTA)	4
Inter-personal violence	4
Conflict	1
Heart problems	1
	30

with these journeys irrespective of sector and the impact of this catastrophic, unplanned, out-of-pocket expenditure on livelihoods and future health seeking behaviours. James (48)[1] describes the costs he incurred leading up to and during his amputation and how, after covering these costs, '*all my capital is gone - I am back to zero*'. He explains that he had heard about the FPRRH workshop from a friend who had paid 1.9 million Ugandan shillings (UGS) (around £400) for his prosthetic leg (at another workshop); '*I was very discouraged at the time because I had spent a lot of money on my treatment and was no longer working.*' James' reactions were shared by many amputees whose livelihoods and access to funds were wiped out even before considering rehabilitation services.[2]

Injuries and Emergency Medical Services in Global Context

Eighty per cent of all deaths resulting from injury (whether intentional or unintentional) occur in LMICs (Kobusingye et al., 2001). Injuries are acute events by their definition and nearly all require emergency care. Werner et al. describe the burden of emergency conditions in Uganda as 'devastating' reflected both in high mortality and morbidity (2021: 2). World Health Organisation Guidelines for essential trauma care (Mock, 2004) describe the importance of urgency when dealing with 'serious time sensitive illnesses' (Ningwa et al., 2020) and outline 3 broad sets of essential needs of the injured patient. The first and third concern the immediacy of treatment (to maximize the likelihood of survival) and the management of pain. It is interesting to see the attention paid (in the second set) to ensuring that: 'Potentially disabling injuries are treated appropriately, so as to minimize functional impairment and maximize the return to independence and participation in community life' (2004: 11). It is impossible to know how many people in similar situations to our sample have lost their lives or how many could have avoided limb loss (and the need for prosthetic devices) had they been treated sooner and more effectively. 'Time' is mentioned 39 times in the WHO Report with specific reference to referral times to tertiary care; transportation times

[1] This refers to the case number.

[2] Amputees are required to bandage their residual wound for a minimum of 2–3 months prior to the fitting of any prosthetic device as the stump will shrink (atrophy) during this time an achieve a stable size.

and Decision-Operation Intervals between admission to tertiary facilities and emergency surgery. All these delays were present in our sample.

Hirshon et al. argue that the 'predominant conceptual framework that divides health problems into communicable diseases, noncommunicable diseases and injuries has contributed to service fragmentation or splintering'. Acute care, they contend, is best defined by reference to the 'singular attribute of time; the need for rapid intervention to get patients to the right place at the right time for the right intervention' (2013: 386). This, they argue can promote greater service integration blurring lines between health promotion, prevention, cure, rehabilitation and palliation.

Uganda's Health Sector Development Plan (2020–2025) describes the at-scene emergency care system as, 'non-existent'; emergency medical transportation systems as 'ineffective' and emergency units in receiving hospital as 'non-functioning' (UMoH, 2020: 174). Ningwa et al. (2020) used a cross-sectional national survey to examine the state of emergency medical services in Uganda. They found an 'unstructured emergency medical services system hobbled by lack of national policy, guidelines and standards; funding; medical products and co-ordination' (p. 8). Only 30.8%[3] of the 52 pre-hospital providers assessed had equipped ambulances, medicines and personnel. Traffic police and bystanders were the first responders in over 90% emergency cases. The authors report a severe lack of equipment and medicines at all levels and across all facility types although they suggest that private facilities are slightly better equipped. In 2021, the National Emergency Medical Services Strategic Plan set out intentions to procure ambulances (with a target of 50 per year), establish an EMS Call Centre and emergency hubs, train EMS cadres, establish and functionalise High Dependency Units in Regional Referral Hospitals and establish referral guidelines (2021: 76). Whilst outlining an 'Emergency Medical Services Call and Dispatch Centres Project' it explicitly acknowledges the need for financial support from global partners (p. 174). None of this is yet realised. This illustrates one of the persistent weaknesses in health planning in Uganda where the Strategic Planning process itself is typically funded (and structured) by foreign organisations and no budgets

[3] In our experience this is a significant over-estimate and fails to account for the routine charging (and over-charging) of patients for hospital transport. Paramedics do not exist as such in the Ugandan setting.

are in place prior to that process.[4] It is almost as if such Plans have an exclusively aspirational/advocacy role presenting options for public but also external funders. A reversal of this process commencing with the public budget and planning within those constraints (starting with the budget) is likely to increase the chance of at least some national commitment and implementation.

Road Traffic Accidents and Major Limb Loss

Goal 3.6 of the United Nations 2023 Agenda for Sustainable Development focused on reducing the number of road traffic deaths by 50% (United Nations, 2015). This was not achieved, and deaths continue to rise in many LMICs including Uganda (Diamond et al., 2018). Road Traffic Accidents (RTAs) are projected to cause 13 m deaths and 500 m injuries during the next decade, hindering sustainable development in LMICs (United Nations, 2021) where investment by global powers is reshaping traffic infrastructure (Diamond et al., 2018; United Nations, 2015). WHO data suggests that road traffic accidents in Uganda cause 29 deaths per 100,000 people p.a., compared to 24.1 for Africa as a whole and 18.1 globally. RTAs in Uganda increased by 42% between 2020 and 2021 and by another 17% between 2021 and 2022 (Walekhwa et al., 2022). In a population survey, 12% of Ugandans reported experiencing serious injury, of which 46% were transport related (Diamond et al., 2018).

Uganda's Health Sector Development Plan 2021–2025 recognises that Uganda has one of the highest incidences of RTA trauma in Africa, but few dedicated emergency medical services (EMS) and no comprehensive public ambulance service (UMoH, 2020). The Commissioner for Emergency Medical Services in the Ugandan Ministry of Health reported that 'many accident victims die before treatment due to lack of first aid'[5] and

[4] The National Emergency Medical Services Strategic Planning process was funded by a US NGO, Homepage—Clinton Health Access Initiative (https://www.clintonhealthaccess.org/).

[5] During the process of data analysis, it became obvious that the cases we were reviewing were those of survivors and many more people in a similar situation would have lost their lives, not 'just' their limbs.

in over 87% cases, patients 'went to hospital on their own' (New Vision, Nov 17, 2020).[6]

Huck et al. (2022) found that attempts to address accidents are prevented by the lack of a robust continuum of care. In the case of RTAs, there is exceptionally low seatbelt/helmet use compared with other sub-Saharan African (SSA) countries (Diamond et al., 2018) and little attention has been paid to the need to engage communities in road safety and accident prevention. The inability to respond effectively to medical emergencies remains a 'major deficiency' (UMoH, 2021). Many people who experience road traffic accidents do not reach hospital quickly enough, leading to adverse outcomes.

Research on the prevalence and causes of major limb loss (MLL) undertaken by Huck et al. (2022) in the Acholi subregion of Uganda found that after war (>49%), many of which are legacy cases, the most common current cause of Major Limb Loss was accidents (29%, of which 42% are RTCs). The prevalence of injuries caused to motorcycle riders (either in a personal or professional capacity) supports Vaca et al.'s concerns about the risks associated with motorcycle taxis locally known as 'boda-bodas' (2022). Of note, however, is the number of pedestrians injured. This echoes concerns about the behaviour of vehicles and motorcycles but also the general lack of provision for footpaths and street lighting outside of major cities. Where footpaths do exist in Kampala, for instance, these are commonly used by boda-bodas to avoid traffic at peak times putting pedestrians (or cyclists) at very high risk. Of the 7 pedestrians injured in our sample, 4 were adults walking to or from work and 3 were children walking to or from school. Osuret et al. (2024) found that pedestrian injuries make up 34.8% of road casualties in Uganda and attribute this, in part, to poor road crossing behaviour amongst school children.

Joseph's case illustrates the devastating, life-long, impact of such accidents. Joseph was walking home from school at the age of 19 when he was hit by a car. In common with many children in Uganda Joseph was living with an auntie a long distance from his father:

> After the accident I was taken to Masindi General Hospital. They just bandaged the leg and referred me to Kilembe Mines Hospital (a PNFP

[6] https://www.newvision.co.ug/news/1532466/gov-provide-emergency-care-team-handle-accidents.

> facility) in Kasese (337km away) because it was near my home. My dad and auntie paid about 9 million UGS (£1900[7]) in the hospital so the money was not there for school fees. After healing my father told me I was not going back to school. (47)

His case illustrates a number of common themes explored in this chapter. Firstly, the risks to pedestrians. Secondly, the complex journeys made by patients both geographically and transecting health sectors and, finally, the catastrophic costs involved.

Catastrophic Out-of-Pocket Costs Arising from Emergency Care

Not all respondents were able to give full details of the costs they incurred between their accident and subsequent amputation. In some cases, extended family had paid, and, in others, they could not recall the details. But many had exceptional recall and provided detail of their expenditure. What became clear was that the costs of accessing emergency services in public facilities, where services are nominally free of charge, were often higher and far less predictable than costs in private or Private-Not-For Profit (PNFP) facilities. It is interesting to note the lack of explicit recognition of Out-Of-Pocket-Expenditures incurred in public facilities in Government documents. A Press Release on the proposed National Health Insurance Scheme, by way of example, states that 41% health expenditures in Uganda fall into the individual 'out-of-pocket' category and concludes, 'This implies that when services are not available at Government facilities, patients have to pay for them in the private sector' (Press Release Proposed National Health Insurance Scheme Bill, 2019). This implies that government services in Uganda are actually provided free of charge whereas the reality is that people expect to pay for all public services. This has a major impact on public behaviour and outcomes.

In a unique qualitative study of the impacts of out-of-pocket payments for surgery in Uganda, Anderson et al. (2017) interviewed 295 out of a possible 320 patients accessing surgical care at Mbarara Regional Referral Hospital in Western Uganda. Basing their analysis on the World Bank's

[7] Costs are cited as Ugandan Shillings (UGS) and a conversion at November 2024 prices is given in brackets.

definition of extreme poverty (based on expenditure rather than income) they found that 46% patients met the criteria of 'extreme poverty' even before admission. The impact of accessing surgical care (and over 75% cases were for emergencies) precipitated a 'financial catastrophe' for most patients even though services in a government hospital should be free of charge. The impacts for patients not having a caesarean section were most profound. The authors contend that this reflects the 'years of attention to maternal mortality by the international community' and associated funding (p. 9).

Many of our sample spoke of having to pay very high and unpredictable sums of money when accessing public emergency services. By way of example, Peter (53) was asked by a public (General) hospital to pay 2.5 million UGS (£530) '*because they didn't have most of the things to be used and had ordered them from Kampala*.' After several days, he describes his leg as 'looking rotten' so he referred himself to a PNFP hospital in Kampala some 300 km away where he was amputated. However, '*the sepsis continued, I had a second amputation, and they told me I had to pay for Vac dressing, there is a machine they connected to the wound, and it sucks the pus. I had to pay 800,000 UGS (£170) a week for 3 weeks (2.4 m UGS or £507 in all for the machine)*'. Peter spent 3 months in that facility and paid a total bill of 41mUGS (£8767). He describes how he had to sell two plots of land at home to make these payments.

Whilst such payments are often articulated as payments for medical supplies (rather than payments to staff) this is rarely accurate. Patients were often also paying for basic (respectful) care (Ackers et al., 2018).

Solomon (34) suggested that he was asked to pay for medicines in Mbarara RRH, but his bill came to 3mUGS (£634). He had to sell his cow to cover this cost. It is highly unlikely that this fee only covered supplies. The reference to supplies is used to conceal endemic charging in public facilities. Even where patients are asked to provide supplies in kind (to conceal cash charging) they are often required to buy more consumables than are required with the excess being sold or used in private clinics. Sadly, this includes charging for blood.

David (9) was first taken to Kayunga General Hospital but as they were unable to treat him, he was taken from there to Mulago National Referral Hospital (60 km). There is a general mistrust (fear even) of Mulago hospital in Uganda that led David's parents to take him instead to Jinja Regional Referral Hospital (50 km) where '*I was taken to theatre 3 times and asked for 300,000 each time (1mUGS or £211 in total)*'. So, David

passed through 3 public hospitals and ended up paying over £211 for his amputation. This case illustrates the impact patient and family's experiences and perceptions of the quality of care have on decision-making. Kobusingye et al. report similar experiences and the contribution these make to delays; 'When the quality of care at hospitals is poor and leads to death, communities may be discouraged from promptly taking patients to such facilities even when the capacity exists to transport patients there' (2004: 627).

In another case, Robert (11) describes how he was charged 3.5mUGS (£740) for amputation at Mulago Hospital. The same story can be seen in Regional Referral Hospitals. Rita, who was only 3 when she lost her leg, describes her parents paying over 3mUGS (£635) to Mbarara RRH.

By way of contrast, James (48) was taken to the nearest private hospital following his accident where he was amputated at a total cost of 2mUGS (£423). It is interesting that he describes it as, '*a private facility, many people cannot afford his services*'. In practice, £423 is less than most people paid when accessing public services.

We saw the costs involved in Peter's stay in a PNFP facility (above). Certainly, PNFP does not mean free or necessarily subsidised care. Joshua (44) paid 1mUGS (£211) for an amputation in Kilembe Mines Hospital, a hospital funded through a PPP/H linking the public and PNFP sectors. Patrick (43) describes how he 'paid 1.5mUGS (£317) to the Doctor (in a PNFP facility) who amputated me and 3.4mUGS (£720) to the hospital.'

Patrick's case illustrates the complex interface between public and PNFP facilities with doctors funded to work in public hospitals often treating patients in private facilities. In this case Patrick describes how he was first rushed to Fort Portal Regional Referral Hospital for treatment:

> I spent there one week but I did not get enough treatment. A doctor told me to go to Mbarara (another public referral hospital) to see a specialist. When we called the specialist, he said he was coming to treat someone else in Kabarole Hospital, PNFP facility in Fort Portal. I was transferred to Kabarole hospital and spent one week waiting for the doctor.

It is usual for patients or families in Uganda to contact individual doctors rather than hospitals a such. The peripatetic role that these (government employed) doctors play hopping between facilities either on more than one payroll (or employment) or, as in this, case extracting a private fee illustrates some of the pressing human resource management problems

that contribute to serious delays and high costs in patient care even in emergency situations. Patrick had to wait for a week to be amputated.

Ningwa et al.'s study of emergency medical services in Uganda concludes: 'The limited availability and functionality of medical equipment for responding to medical conditions means patients were getting very limited care in the pre-hospital phase, and then being transported to health facilities that were only marginally better equipped to manage their acute events' (2020: 8). This certainly resonates with the experience of many of our sample who were bumped between facilities until they finally reached one able (or willing) to amputate.

Pickering et al.'s (2022) study of patient and caregiver's experience of accessing Emergency Departments in rural Uganda adopted the '3-delays' model first developed to highlight the underlying causes of maternal mortality (Thaddeus & Maine, 1991). Their findings indicated 4 factors contributing to significant delays in presentation at Emergency Departments including:

1. Cultural factors and limited knowledge of emergency signs and appropriate actions to be taken.
2. Use of local health facilities despite perception of inadequate services.
3. Lack of resources to cover anticipated costs of obtaining emergency care.
4. Inadequate transportation options.

The lack of ambulance services has been noted. Most of our sample used private means, including boda-bodas to access services and, in many cases, as we shall see, this involved complex journeys between different facilities. The role of cultural factors is discussed in more detail in the following chapter where witchcraft and local healers contributed to delays leading to sepsis. The interviews identified several cases where patients were reluctant to agree to amputation. Robert describes how he '*feared to be amputated and only decided after 3 days*' (11). Joseph (47) took 2 weeks to agree. Paul describes his reluctance and preference for local healers:

> On arrival at Kilembe (PNFP) hospital the doctors immediately suggested an amputation. I refused consent and asked to be taken to Masindi because I had heard that my bones could be aligned using traditional means. My condition worsened in the next hour because of profuse bleeding, and

> I got weaker by the minute. My uncle arrived and gave consent on my behalf. He reassured the doctors that he would take responsibility for this decision, and I was immediately rushed to operating theatre. (46)

Pickering et al.'s study only assessed delays leading up to admission to the first health facility and did not consider subsequent delays. They did recommend the need for further research to address referral network interventions. One of the shocking findings of our study was the sheer complexity of people's journeys to amputation (Table 2.2).

According to the UMoH's Comprehensive Health Service Standards Manual, emergency amputations should be performed by general surgeons based in a network of District hospitals (2021: 11). According to this manual, each District Hospital should serve a population of around 500,000 people. Where people first access lower-level facilities for emergency first aid, these should be available at all Health Centre 3 and 4 government facilities at least during the working week. Level 4 facilities have operating theatres and are staffed by doctors and anaesthetic officers. Where essential the Manual suggests that doctors in Level 4 facilities should also perform 'lifesaving surgical operation'. However, where time permits and access is possible, most cases requiring amputation should be referred to the nearest District Hospital. Only seven of the 26 cases in our 'injury' sample passed through a General Hospital at some stage. Amputation took place at the receiving General Hospital in only one case and involved a journey of 39 km (20). In 4 cases the patient was referred on to the National Referral Hospital; a journey of 89 km (11), 119 km (9) whose journey commenced in a public health centre and 260 km (37) respectively. Three cases involved direct referrals to a Regional Referral Hospital (with one of these going via a public health centre).

Derrick's case (36) illustrates the complex relationships that exist between the public, private and PNFP sectors in Uganda and the delays and costs involved. Derrick first accessed the National Referral Hospital where he was advised by a doctor to attend a separate private clinic for a scan. On receiving the result, the same doctor sent him to the Mulago Heart Institute[8] for an operation on a blood clot. He was then connected

[8] The Ugandan Heart Institute is an interesting example of the fusion of public, private and PNFP status. Nominally it is Uganda's flagship specialised *public* facility owned by the UMoH. One of Uganda's national newspapers reported the success of the facility which can now 'handle over 95% adult cases and 85% cases among children in Uganda

Table 2.2 Distances travelled to facility performing amputation and journeys involved

	Case number	*Total distance from accident to facility conducting amputation (km)*	*Facilities accessed on journey from incident to amputation facility by sector and type*
Amputation in general hospital			
1	20	39	GH
2	9	119	HC-GH-RRH
Amputation in regional referral hospital			
3	49	2	RRH
4	50	26	HC-RRH
5	34	26	RRH
6	8	35	RRH
7	32	20	PC-RRH
8	19	32	PC-RRH
9	30	32	PC-RRH
10	29	128	PC-RRH
11	6	15	PNFP-RRH
12	51	112	PH-RRH (including bone healer)
13	52	166	HC-PC-GH-HC-RRH
14	60	28	RRH
Amputation in National Referral Hospital			
15	11	89	GH-NRH
16	37	260	GH-NRH
17	35	280	PC-RRH-NRH
18	13	49	PNFP-NRH
Amputation in PNFP			
19	53	300	GH-PNFP
20	43	50	RRH-PNFP
21	5	31	PNFP
22	44	12	PNFP
23	47	337	GH-PNFP
24	46	52	PC-PNFP
25	58	40	PNFP
26	59	40	PNFP
Amputation in private hospital			
27	48	7	PH
28	3	740	GH-PH-PNFP-PH-PH (including 2 bone healers)
29	54	80	PNFP-PC-PC
Health Centre IV			
30	36	551	NRH-PC-PC-PNFP-HC

Key HC = Public Health Centre; GH = Public General Hospital; RRH = Public Regional Referral Hospital; NRH = National Referral Hospital; PNFP = Hospital in Private Not-for-Profit Sector; PC = Private Clinic (incl. local healers); PH = Private Hospital

to another doctor in Mulago Hospital who '*promised to operate on me from St. Stephen's Hospital (PNFP). He asked me much money - 4mUGS (£845) to operate. We looked for money everywhere*'. After discharge Derrick continued to experience severe pain. At this point his sister, who lived in Mbarara (270 km away) advised him to travel there to see a friend who was a doctor; '*Next morning l was taken to Mbarara and was asked to do another scan which showed that l still had blood clots. The doctor connected us to another doctor in Kampala since my condition was beyond his level. The next day l was taken back to Kampala (270 km). The doctor asked us to do some tests and then asked us for 2.5mUGS (£528) before he operated me*'. Four days later he was still in pain and had started to lose his toes. The doctor referred Derrick back to the NRH. At this point he had breathing problems and required an ambulance; '*The doctors at Mulago connected me to another doctor who performed the amputation at Kasangati Health Centre 4 facility and charged me 1.5mUGS (£317)*'.

Derrick's case illustrates several factors contributing to his declining health and delays. It is quite shocking, having accessed the National Referral Hospital (Mulago) and a specialist facility linked to it to then face a long journey to a distant Regional Referral Hospital only to be referred back to the National Referral facility. Cash changed hands at each stage. The fact the amputation (in such a high risk and complex case) finally took place in a lower-level government health centre suggests that the surgeon was using that facility (inappropriately) for his private gain.[9]

Compounding the impact of these complex and time-consuming journeys, many respondents identified extensive delays in accessing care at facilities as a direct result of health worker absenteeism, particularly amongst doctors (Ackers et al., 2016). Ningwa et al. (2020) found that in 18.4% cases hospitals (including RRHs) did not provide 24/7 services.

In many other cases patients who accessed public hospitals, including the National Referral Hospital in Kampala described having to wait days to be seen. This is a particular problem in the days leading up to, during

(which) is line with the National Development Plan II (NDP2) strategy of reducing referrals abroad to less than 5%' New Vision (26 August 2021). "Uganda Heart Institute Tasked To Retain Specialists". *New Vision*. Kampala, Uganda. Expansion plans in 2024 were supported by loans from Arab sources amounting to 96% total funding and contracts awarded to Arab Contractors Uganda Ltd. "Uganda Heart Institute: Tribunal Upholds $45.4 m Contract Award". *The Observer (Uganda)*. Kampala, Uganda.

[9] Other instances of these amputations taking place at Kasangati have been reported to us during the study.

and immediately after weekends when doctors are often absent from public facilities. Charles' case is typical: '*I was admitted (to a RRH) but didn't get medical care for 5 days from Friday to Wednesday. [On Wednesday] the doctor asked me to take a scan after which he said he will have to amputate my leg*' (19).

Geoffrey had a similar experience. On the day of his accident, he didn't have the funds to pay for admission to the nearest RRH. His family raised the funds enabling him to travel the following day which was a Friday: '*I was admitted but no doctors were available until I saw a physiotherapist on Monday and was sent to X-ray. On Wednesday the doctor suggested to cut off my leg*' (30).

Tom's case is even more worrying: '*I spent five days in Mbarara hospital waiting for the surgeon to see me and that's when l was told the Doctor was not going to come. I was then referred to Mulago National Referral Hospital (280 km) because we had waited for long, and the doctor was nowhere to be seen. When we reached Mulago we were told that we delayed for so long the clot (in his leg) was now very dangerous. We got to Mulago hospital on Friday and were told to wait because it was already weekend, and some doctors were not around. On Monday the doctors reviewed me and that's when l was given the horrible news about amputation*' (35).

John (32) was taken to Hoima Regional Referral Hospital on a Monday after a major crush injury needing emergency surgery, but the next theatre list took place on the Thursday leaving him waiting for 4 days. He believes that this may have led to more invasive surgery and greater limb damage.

The cases above evidence the contribution that absenteeism makes to extensive delays, complex journeys and catastrophic costs.

Accidents in the Course of Employment

One might expect that employees injured in the course of their employment might be better supported than other cases. Brian's case is highly complex and illustrates the experiences of quite a few respondents who were injured in the course of their employment. Whilst employers sometimes helped out in the initial first aid, it was unusual for them to cover all the medical costs, and no respondents retained their employment or received any compensation.

Brian (3) was injured when a forklift truck they were using dropped solar panels on his leg. In the first instance the company sent him directly

to a public hospital supported by the Chinese Aid Foundation in Kampala (Naguru Hospital) for emergency first aid and to stabilise his condition. Support from his employer ended there. He then travelled to the RRH nearest to his home in Mbarara. Unable to make any payments to the (public) hospital Brian explains that the '*doctors refused to work on me*' so he sought help from traditional healers in his local village. As his condition deteriorated, he travelled to CORSU, a large PNFP facility in Entebbe because, '*the government hospital wanted money but didn't ask for it*'. We can interpret this as meaning that the pricing mechanism at CORSU was transparent whereas at Mbarara it would involve a complex and opaque series of informal charging (or bribes). CORSU, despite its not-for-profit status, required 8.5mUGS (£1800) to undertake his operation. Unable to afford this he was taken to an informal '*bone healer known to repair fractures*' near Jinja (120 km).[10] Brian was later sent to a private facility, Kayunga Medical Centre, for surgery to put a steel plate in his leg at a cost of 500,000UGS (£106). As this was unsuccessful, he was later amputated at the same facility at a cost of 12mUGS (£2536). Brian was forced to sell land in his home village to cover these costs. When he was discharged, he returned to his home village and had his wound dressed in a local private clinic at a cost of 1.3mUGS (£275).

Brian's case illustrates several common experiences. In the first instance, the costs involved in managing the emergency care involved in major limb damage. The actual costs and anticipated costs of accessing care have a catastrophic impact on personal and wider family finances. Brian is one of many respondents forced to sell land, at very short notice, to fund lifesaving surgery. The loss of that land is also a loss to his and his family's future livelihood. And this is particularly true for amputees who are often unable to continue with their previous employment and relocate, as Brian did, to be near family support in his home village. Brian accessed private facilities even though he lived close to the second largest city in Uganda with a very large Public Referral Hospital. His case illustrates another issue that emerged in 5 interviews; namely of employer liability for injuries sustained in the course of employment. The Workers Compensation Act (Uganda, 1961), Section 18 states that Workers' Compensation Insurance is mandatory for all businesses operating in

[10] The role that traditional bone healers play is discussed in Chapter 3 in more detail.

Uganda, irrespective of size. Section 18 of this Act provides for compulsory compensation to workers for injuries suffered in the course of their employment. This law applies to all employees within Uganda, except for active members of the armed forces. Under the Act, the employer is responsible for personal injury by accident if it arises out of and during a worker's employment:

> Where an accident occurs entitling the worker to compensation under this Act, the employer shall defray the reasonable costs incurred by the worker (a) in respect of medical expenses; and (b) in respect of transport and incidental expenses, arising out of and in connection with the accident.

The Act clarifies the scope of coverage as extending beyond first aid to include rehabilitation:

> 'Medical care' means medical, surgical and hospital treatment, skilled nursing services, dental care, physiotherapy, rehabilitation and the supply, maintenance, repair and renewal of artificial limbs or any other artificial appliances or apparatus'.

Only in 1 of our cases did the respondent report having his costs covered and this was a case involving a member of the armed forces. The other cases received little if any support beyond immediate first aid.

Brian was employed by a large company. In the first instance the company did support him to get emergency first aid. But at that point it withdrew its support and failed to take responsibility for his injury, to cover his medical costs and offer compensation. He also lost his job as a result. Brian had made serious attempts to pressurise the company to support him but the significant costs of taking legal action overwhelmed him. He also sought support from the Ministry of Employment (as specified in the legislation) but with no success. The total cost of his amputation came to nearly £3000 excluding the costs of transport, care, subsistence and loss of earnings.

In a similar case, Paul (46) was crushed whilst disembarking from the truck he drove for a well-known cement company: '*My colleagues put me in their truck and drove me to Rwimi (10 km) where I was collected by an ambulance sent by the company and rushed to the factory clinic for first aid. They gave me some pain relief medication and a tetanus shot and referred*

me to Kilembe Mine Hospital for amputation 42 km away' (46).[11] In this case the company covered the cost of the ambulance and his amputation but failed to honour the compensation or subsequent rehabilitation and he lost his employment with them: '*My employer paid my hospital bill because I got into an accident while I was on duty. They promised that an insurance company would pay out money to support me after my recovery, but nobody got back to me*'.

In another example, Tom was a driver working for a company carrying food stuff. He sustained an accident whilst driving a truck in Mbarara (his home city). When he was eventually amputated, he was taken to theatre 3 times and stayed for 3 months before he discharged himself: '*I wasn't fully healed but because of the financial constraints. I didn't have any more money, and my little brother was taking care of me. He was supposed to be at school, so we decided to go home*' (35).

Tom received no support from his employer at all. In another case, William was electrocuted whilst working on a building site in Kyenjojo District. He describes how he had to delay attending the public hospital due to lack of funds: '*As we were looking for money for 10 days the leg had deteriorated. The doctor decided to amputate to prevent any risk of infection to other parts. I was discharged to heal from home after 2 weeks and returned to remove stitches*' (29). William didn't disclose how much the Regional Referral Hospital had charged him for his care, but it was clear that his employers provided no support.

Another case involved a student employed in a sawmill during his vacations. John (32) fell into the saw and lost his hand. In this case his colleagues took him to the nearest local private clinic owned by Bugambe Tea Estate. Once again it was clear that the company employing John, albeit on a casual basis, took no responsibility for his injury. Other cases involved people injured in the course of their employment but in their own small businesses often in the food industry or as boda-boda drivers.

[11] Kilembe mines hospital is run on tri-partite arrangement (Joint Administrative Agreement) between the Government of Uganda, Kilembe Mines Ltd and Kasese Catholic Diocese.

Inter-Personal Violence

Four of the 30 emergency cases involved acts of inter-personal violence. Inter-personal violence is very common (normalised) in Uganda. According to the Ugandan Demographic and Health Survey, 44% women and 39% men reported experiencing 'physical violence' (by any perpetrator) in the preceding 12 months (UDHS, 2022). The first case in our sample involved a violent attack on a guard during his work. Fortunately, in this case, his employer did honour his legal obligations. Patrick was 46 years old and working in an abattoir when thugs came and attacked him:

> Unknown people came to the farm when I was the only one there. When I heard dogs barking, I opened the door and a man with a panga (machete) wanted to cut off my head. I guarded it with my right hand and the hand was cut off from the wrist. At Kabarole Hospital they gave me first aid, and, in the morning, they transferred me to Fort Portal Regional Referral Hospital where I spent one week as they were cleaning the wound. They took me to theatre and removed my arm below the elbow. My employer paid all the bills at the hospital including buying drugs and transport. (6)

In another case a 14 year old boy was attacked during a family dispute over land. Violence over land is sadly very common in Uganda:

> I was going to school one morning I met a man who cut it off. There were some land related disagreements they had with my uncle. Someone died in the other family and [my uncle] was accused of killing that girl. So that family resolved that they should kill his people as well. They ambushed us in the road and mutilated us. They used a panga to cut off my hand and it fell off right there. I was rushed to Buhinga hospital. (P1)

Two cases involved intimate partner physical violence.[12] In 2017, Ninsiima, at 8 months pregnant, was the subject of a vicious attack by her husband resulting in the loss of both hands. This is not an uncommon outcome of Intimate Partner Violence in Uganda and many other countries (EPRC, 2022). Upper limb amputation entirely marginalises these commodified women placing them in extremely vulnerable economic,

[12] A further case was included in the Upper Limb study reported on in Chapter 7.

social and personal positions. Susan was also a victim of extreme intimate partner physical violence:

> I had an argument with the father of my kids, and I left his place and went back home with my children during the Covid lockdown. After one week and 4 days as I was coming from town the father of my children was hiding in a small bush with a panga (machete) and he jumped out and cut me three times in the head and arms. So that is how I lost my arm. He ran away and has never come back. We engaged the police, but they needed money to continue with the process of tracking him which we didn't have, and I was still footing my medical bills so since then we have never seen him. (13)

In May 2022, K4C established the first Rehabilitation Centre for people with limb loss in a Ugandan public hospital. The Centre was named after Ninsiima in recognition of the role she has played in stimulating this process. Lady Justice Margret Mutonyi opened the Ninsiima Centre with a speech reporting a series of other cases of bilateral upper limb loss known to Ugandan Courts and calling for a more holistic approach to the needs of women suffering catastrophic limb loss and damage because of IPPV. This included a case of a mother of 9 children who lost both hands (and 3 of her children) through a violent machete attack on the grounds that she bore twins. In another case, Mutonyi reported a bilateral amputation on suspicion of adultery. Sadly, similar cases are reported by research colleagues in Tanzania, Kenya and Cambodia.

Recent research on the global prevalence of 'traumatic' limb amputation (McDonald et al., 2021), whilst failing to report on gender specifically, identifies some disturbing trends. Referring to traumatic limb loss as a 'neglected epidemic' in LMICs and highlighting the dearth of accurate data, analysis of existing data indicates a much higher prevalence of upper limb loss than expected. Furthermore, according to McDonald, an equal proportion of people who suffer upper limb loss, lose both arms. Indeed, where the cause is reported as 'interpersonal violence' more victims lose both arms than one (482 as compared to 429).

The term 'Intimate Partner Violence' (IPV) describes abusive behaviours between partners in an intimate relationship and can broadly be classified as abuse of a physical, emotional or sexual nature. Intimate Partner *Physical* Violence (IPPV) focuses on violence that causes physical injury. IPPV is a global phenomenon with women in all countries

and contexts at risk of violent behaviour in the privacy (and invisibility) of their own homes. Evidence on IPPV and its impacts is undermined by underreporting linked to stigma, embarrassment and gender norms rendering it acceptable or inevitable. Women are also deterred from reporting incidents to the police as they are aware that they will (always) be expected to pay costly bribes for action and their partner (and his family) may be counter-bribing. Reporting incidents is likely to stimulate further violence and punishment from the husband's family, often supported by the mother-in-law. Existing research, based primarily on secondary data, identifies a high prevalence in LMICs and Sub-Saharan Africa (SSH) (Devries et al., 2013). High rates are also reported in Bangladesh (Islam et al., 2021). Recent research in Cambodia (Astbury & Walji, 2013, 2014) focused on the specific vulnerabilities already-disabled women face and identifies trends that normalise IPV and silence victims. The paper cites a Ministry of Women's Affairs finding that, '*More than half of all Cambodian men and women believe that even extreme partner violence such as stabbing, shooting or throwing acid at a wife is justified if she is argumentative or disagrees with her partner*' (2010). 80% of acid attacks in Uganda's National Referral Hospital are related to IPPV. The ready availability of secondary data (Official Statistics) has encouraged a number of multi-country, comparative, studies reporting prevalence and survivor characteristics. McClintock et al. (2021) analysis of Demographic Health Surveys across 8 SSA countries reports a lifetime prevalence of physical violence at 35.63%.

A number of Ugandan studies (Gubi et al., 2020; Kiwuwa-Muyingo & Kadengye, 2022; Kwagala et al., 2013; Speizer, 2010) analysed data from the Ugandan 2016 Demographic and Health survey. Gubi et al., 2020) found that more than half (56%) of married women experienced some form of IPV. The most recent (2022) Uganda Demographic and Health Survey (UDHS) reports some improvement in trends. It also reports data on male experiences of spousal violence Table 2.3).

When alcohol is factored in, the proportion of women experiencing spousal Intimate Partner Violence increases considerably (Table 2.4).

Speizer concluded, 'a high percentage of women and men have attitudes supportive of wife beating and women are significantly more likely to report supportive attitudes than men' (2010: 13).

The F4P study included a focus group with several women waiting to receive prosthetic devices in the FPRRH Workshop. Services were delayed for 3 weeks due to the lack of materials (in this case Plaster-of-Paris) and

Table 2.3 Prevalence of spousal violence by marital status

	Married/Cohabiting (%)	*Divorced/Separated/Widowed*[13] *(%)*
Wives	52	59
Husbands	32	52

Source UDHS (2022)

Table 2.4 Percentage of ever-married women who have ever experienced spousal (physical, sexual, or emotional) violence by their husband/partner)

Husband/partner does not drink alcohol	44%
Drinks alcohol but is never drunk	54%
Is sometimes drunk	64%
Is often drunk	84%

Source UDHS (2022)

the women were asking why it was that they couldn't personally pay for these materials so that they could return home. Concerns about domestic violence (and an acceptance of this) emerged:

> I cannot even dare go home without a new leg because for married women like myself, my partner would suspect me of unfaithfulness. He could think I went to stay with a lover under the disguise of getting a leg. He would not believe me if I went home without a new leg after 4 weeks. He would say, 'I have never seen you having to wait for a leg for a month and then coming back with none.' Our partners are used to us spending a maximum of two weeks here but if I spend a month and worse still go home without a leg, he will never believe my story. Some can get violent and hit you. I would allow him to hit me because he would be right in thinking that way. (FG)

Another woman commented: '*He gave me permission to come here on the condition that I spend two weeks and come back with a leg none of which I have been able to do. I am worried about my marriage. If my partner hits me he would be right. He gave me the transport fare and money for*

[13] The published report is not clear why widowers are included in this data.

upkeep for one week and sent more for the second week. How then can I go back home after 4 weeks without a leg? My pleas and explanations of the situation would go unheard. He would question my logic and think I am not telling the truth' (FG).

This 'acceptance' of IPV amongst victims is substantiated by Bukuluki et al. who conclude that high levels of IPV in Uganda are, 'sustained by a bedrock of harmful social norms that perpetuate physical violence against women' (2021a: 12). This normalisation is rarefied in conflict and post-conflict areas. A cross-sectional survey of refugees during the pandemic using computer assisted interviews found that, 'tolerance of violence is higher amongst women in conflict zones' (Bukuluki et al., 2021b: P9). This supports Black et al.'s analysis of UDHS for the Gulu region of Uganda (2019) which reported that 80% of women had experienced at least one type of IPV in their lifetime, and 55% of women had experienced IPV within the past 12 months. Recent work reports the impact of lockdowns, school closures and socioeconomic hardships during the COVID-19 pandemic (Forry et al., 2022).

Many studies report a relationship between both incidence and normalisation of IPV and (low) socio economic and educational status and religion (Houston-Kolnik et al., 2019; Muhanguzi et al., 2011; Wood, 2019). However, other work indicates a strong prevalence amongst professional women. Kitara et al. (2012) suggest that the economic independence achieved by women challenges male control within marriage with men resorting to violence to assert their dominance. Amegbor & Pascoe (2021) make a similar point arguing that, 'Although some studies suggest higher socioeconomic status acts as a protective factor.… other studies report that higher socioeconomic status (including employment, financial independence, and property ownership) does not protect women from acts of violence. This is particularly true for patriarchal societies, where asset ownership and economic dominance are seen as markers of masculinity; violence becomes an easy and cheap way for men to establish their dominance' (p. 15).

The work referred to above is important both in understanding the wider parameters of IPV but also in influencing potential responses. Whilst official statistics support the characterisation of societal problems, such data undoubtedly underreports violence but also fails to capture the social processes and meanings that sustain and can change human behaviours. All the studies reviewed conclude with generic calls for educational interventions to address the 'root causes' of gender norms. This

is supported by quite powerful evidence of the intergenerational transmission of violence (Speizer, 2010). Whilst survivors may report the normalisation of IPV this is not the view of the World Health Organisation or the Ugandan Government. Muhanguzi et al. (2011) describe the attention to gender inequality in education in Uganda as a key area of government intervention. This includes the appointment of 'senior women' in schools to guide and counsel students.

It is interesting to note—and this perhaps reflects the nature of the data—that existing research pays scant attention to the criminal justice system in apprehending and incarcerating perpetrators and the role this could play in sanctioning and changing behaviour. The majority of papers advocate 'persuasive' approaches (such as training, Mutabaruka & Kazooba, 2021) eschewing the urgent need for criminal sanction as would take place in any other violent crime. The conclusions arrived at by Darteh et al. typify this 'persuasive' approach: 'non-governmental organizations, civil groups and government agencies should strengthen advocacy against physical intimate violence against women' (2021: 1441). One exception to this is a Zimbabwean paper suggesting that over 60% of criminal cases registered in courts originate from domestic violence (Kitara et al., 2012). There is also limited specification of the health systems implications of IPPV with conclusions often referring generically to poor health outcomes. A rare exception is a study in Northern Uganda based on surgical records. Kitari et al. describe IPPV as 'one of the most pervasive violations of the rights of women and girls and a major public health problem which drains hospital resources'. The authors challenge the dominant view that IPPV is associated with poverty contending that, 'There are scores of well-to-do women in Uganda who are being battered by their husbands, while their plight fails to get public attention' (p. 9). They suggest that stigma leads to under-reporting contributing to the lack of accurate data which, in turn, limits their ability to 'characterize injury due to violence and thereby plan injury prevention efforts (2012: 1). Their prospective study of surgical cases found that IPPV has replaced conflict (and Road Traffic Accidents) as the major cause of surgical cases: 24% of 454 trauma patients undergoing surgery were IPPV cases. They were also able to specify more closely the types of injuries involved with the overwhelming majority being injuries to upper limbs (52.9% or 240 cases) and the head (22% or 100 cases). This study marks a huge step forward in raising the impacts of IPPV on health systems both in terms of costs and service improvement. We can anticipate that many of these

women faced a violent attack aimed at their heads, probably with a machete with limb damage occurring as women attempt to protect their heads with their hands (as in the case of Ninsiima).

The scope of this research and our understanding of the prevalence and impacts of IPPV is inevitably limited by reliance on secondary data. Under-reporting further challenges data accuracy Gardsbane et al. (2022) due to the reluctance to report even severe abuse, 'because of the overarching structural patriarchy and violence that exist' (Amegbor & Pascoe, 2021). Our concerns about the impact of IPPV on upper limb loss in Uganda has stimulated a follow-on piece of work focused on the provision of Koalaa prosthetic arms and wrap-around counselling services for victims.[14]

Conclusions

We opened this chapter with a statement explaining why we have analysed the data on respondents' experiences of amputation in a study focused on rehabilitation services. It was clear from the narratives that their experiences of emergency care services had a major and lasting impact on their subsequent health seeking behaviour. Complex journeys, extensive delays, the lack of employer support all contribute to poor outcomes and catastrophic out of pocket expenditure that effectively exhausts individual and family resources and the potential to generate future income for rehabilitation.

It also reveals wider systemic weaknesses and the need for more holistic, multidisciplinary and less 'boxed-in' approaches to global health. Huck et al.'s paper on the prevalence and spatial patterns of major limb loss in Northern Uganda makes the interesting observation (and projection) that the shift from conflict to road traffic accidents and chronic disease as the trigger for amputation, 'could increase the likelihood of hospital attendance […] which could be beneficial from the perspective of increasing accessed to rehabilitative services, as patients receiving amputation are already 'in the system (as opposed to those who have never received formal medical care' (2022: 377). Sadly, the findings presented in this chapter challenge that assumption. Even in absolute emergencies

[14] The extended discussion on domestic violence is reported here as this is an area that the research team are planning to engage in more actively in 2024/25 with support from the University of Salford.

patients often do not seek or do not receive emergency care in the most proximate hospitals and service integration barely exists. Compounded by the catastrophic costs of the journey-to-amputation which often delays subsequent health seeking behaviour it is fair to say there is no such thing as 'being in the system' at the present time in Uganda. Okello's paper (2019) supports this assertion finding that less than 1% of patients (in Northern Uganda) had been formally referred to rehabilitation.

CHAPTER 3

Patients' Journeys to Amputation (2): Long Term Conditions

Abstract This chapter addresses the role that long term health conditions play in patient journeys to amputation. Particularly diabetes and poorly managed wounds. Echoing Chapter 2 it shows the impact of these conditions and associated delays, exacerbated by poor referral systems and human resource management on amputation rates. It also evidences the catastrophic health expenditures involved and the impact of these on subsequent attitudes towards accessing rehabilitation services. The Chapter highlights the role that beliefs in witchcraft and alternative remedies play in the delays process.

Keywords Diabetes · Human resource management · Long term Conditions · Wound care · Witchcraft

Introduction

Chapter 1 noted the tendency in work on physical rehabilitation services in LMIC settings to focus on conflict as the major cause of limb loss. Whilst there has been increasing recognition of traumatic accidents, particularly road traffic accidents: interest in long term conditions, infections and non-communicable diseases such as diabetes and hypertension has lagged behind. Our sample included a range of cases that can best be

L. Ackers et al., *Delivering Universal Health Care to People with Major Limb Loss or Damage in Low and Middle Income Countries*,
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characterised, generically, as long-term conditions. These include twelve children, ten of which attended the orthopaedic workshop at FPRRH for orthotic devices to treat congenital conditions causing limb abnormalities. The mothers who acted as respondents typically referred to their children as having 'bone deformities' which they often attributed to vaccine damage. The other two were described as amputations arising from early childhood cancers.

Of our sample of 60 people with major limb loss, the majority of amputations in the non-emergency category (15), were tracked back in the interviews to some form of wound. This chapter focuses on these 15 cases. Six were explicitly identified as linked to diabetes although in many cases the causes of the wound and its deterioration are complex. Seven respondents refer to the role of witchcraft as a contributing factor, or to seeking support from witchdoctors or alternative 'healers'. The discussion illustrates the often extensive period of deterioration over time during patient journeys to amputation, the impact of delays in seeking or accessing care and the catastrophic out-of-pocket expenses incurred. Whilst the previous chapter has described some of the 'fuzzy' boundaries distinguishing the private and public sectors, the data reported here adds further complexity in the interaction of 'modern' medicine with traditional ('private-sector') approaches including the use of herbs, witchdoctors and 'bone-healers'. We commence our discussion here with the cases where respondents identified themselves as diabetic. As 60% diabetes in LMIC settings is undiagnosed (Flood et al., 2021) the prevalence of diabetes may impact other cases.

Type 2 Diabetes and Amputation Risk in LMICs

Diabetes is a leading and exponentially increasing, cause of morbidity and mortality in all health systems. Diabetic foot complications are fast becoming the main cause of non-traumatic lower-limb amputation and up to 80% people die within 5 years of amputation (Abbas, 2013; Abbas et al., 2022). Around 25% of diabetics will be affected by a foot ulcer during their lifetime (Armstrong et al., 2017; Singh et al., 2005). According to Abbas et al.'s research in Tanzania (2022) about 85% of non-traumatic amputations are preceded by ulceration. Unsurprisingly, Abbas et al. show that delays in accessing healthcare after ulceration significantly increase amputation risk. One of the most common themes

running through the interviews concerned the role of these delays illustrating once again the value of the '3-delays' conceptual framework. All 3 delays are evident from poor levels of awareness or understanding of their condition; in accessing health care and in the quality of care when patients were able to access it.

Respondents rarely use the term 'ulcer', referring instead to wounds or, quite commonly, 'burns'. It is also clear that they didn't previously anticipate or understand the association of this presenting wound with their diagnosis of diabetes.[1] Or, as in the following example, were not aware that they had diabetes before the wound appeared:

Jovia is 63 years old and lives in Fort Portal. She was diagnosed with diabetes in 2022 when her toe started to go black. She was admitted to FPRRH for 10 days. At discharge she went to stay with her daughter in Ibanda district (some 117Km away):

> One week later pus came, and it started to smell so my sister took me to Uganda Martyr's hospital in Ibanda district (a PNFP facility). When my condition worsened my daughter took me to Kagongo District (public) Hospital for wound dressing and then amputation of my toe. Another toe began to go black so that was also amputated. Then a large deep wound appeared on the bottom of my foot, so the doctors referred me to Rukungiri district to meet a person who dresses diabetic wounds, and I stayed there (for 1 month) with my sister. We were staying in Rukungiri town, and the man used to come home to dress my wounds. After 1 week and no improvement, I decided to come back to FPRRH hospital. The following day they took me to theatre and cut off the leg. (25)

This case illustrates a number of common themes including the lack of a diabetes diagnosis (and treatment) prior to a wound appearing. Jovia had developed gangrene losing two toes prior to ulceration. It also illustrates the desperate 'shopping around' for appropriate healthcare, across all sectors, underlining the lack of functioning referral pathways, the delays involved and the speed with which what may initially appear to be a small injury can precipitate major limb amputation. It is unclear who this 'person' is who has a local reputation for dressing diabetic wounds. He may be a local healer, a herbalist or a nurse. It is very common in Uganda for

[1] Knowledge For Change is currently developing and evaluating a nurse-led diabetes self-management program in FPRRH linked to a novel Diabetic Foot Clinic funded by the Burdett Trust SB\ZA\101010662\898098.

someone to seek out specific individuals they trust or have been recommended to them by family or friends rather than put their trust in public health facilities.

Muzemeza's case is quite different and illustrates the challenges of managing a diabetes diagnosis in Uganda. Muzemeza is a 47 year old peasant farmer and fisherwoman. She was diagnosed with diabetes in 2000 at the Marie Stopes[2] (PNFP) clinic in Fort Portal and advised to change her diet. In 2003 during her 5th pregnancy her diabetes worsened, and she went to (public) Rwebisengo Health Centre IV. Here she was prescribed drugs but as none were available, she bought them in a private pharmacy. She then visited a doctor every 2 months for testing and prescription:

> It was expensive for us. My home was far away from the health centre, but I had a house in Rwebisengo trading centre very near the health centre, so when I got diabetes, I shifted from the village to near the health centre, so I get quick treatment whenever my diabetes gets high.

In 2016 her diabetes worsened and the doctor prescribed injections:

> There were no drugs for injection at the health centre, so I used to buy the medicine from Fort pharmacy but kept them in the fridge in the health centre. The doctor had to give me the injection every morning and evening. I did this for 2 years. In 2018, I started injecting myself from home as I had bought a fridge to keep the medicine safe. In 2021, the diabetes worsened I was rushed to a nearby local private clinic where I knew the doctor and was referred to (public) Rwebisengo HCIV and then on to FPRRH. After one week I felt no better so I self-referred to Mulago (National Referral Hospital) using a private taxi and spent a month there before being discharged and returning home.

On discharge she decided to go to her 'other family' in Kagadi district 252 Km from Kampala. After 3 weeks she fell ill again and went to a private clinic in Kagadi town. Her sister who lives in Bwizibwera near Mbarara RRH said she knew a doctor who could help her, so decided to travel there. Muzemeza describes the journey: '*my feet got burnt because*

[2] Marie Stopes is focused primarily on sexual and reproductive health. She probably accessed their services due to her pregnancy. They don't offer services for diabetics as such https://mariestopes.or.ug/.

of sitting (over the engine) in the car for a long time. My sister took me immediately to Mbarara cancer centre, a private facility. They started to treat my wounds first removing toes then my leg just below knee. Then my wounds started to heal' (16).

Muzemeza's case illustrates the challenges that diabetics face in Uganda when trying to access medications. She clearly made major changes to her life even relocating to be near the health centre. Her struggle to access treatment when her condition worsened in 2021 illustrates the inadequacy of the public facilities, including tertiary hospitals when it comes to diabetes and other non-communicable diseases. On several occasions she talks of trying to access an individual doctor known to herself or her family. This is a very common occurrence in Uganda where people know of or are recommended individuals who they will typically contact privately and may then operate peripatetically, hopping between 'hosting' facilities to deliver private services. It isn't clear why Muzemeza felt that her feet were 'burnt' in the vehicle. We may assume she had a pre-existing problem exacerbated by the long journey and hot floor. It is interesting to note that on arrival at Mbarara she did not even try to access the Regional Referral Hospital but instead selected the private cancer centre.

Edward's case also illustrates some common themes, not only in diabetic cases but also in self-management of infections where patients decide to stop taking (and paying for) medication (Ackers et al., 2020). Edward was 82 years old when his leg was amputated. He had been diagnosed with diabetes many years earlier:

> They gave me drugs to use, and I also used some local herbs. From then diabetes stopped bothering me and I thought it was healed, and I stopped using the drugs. In 2022 my leg became swollen, so I came back to FPRRH. The doctors told me my diabetes was high and said they have to amputate my leg. (07)

In common with many other patients Edward combined the use of prescribed drugs with local herbal treatments provided by private suppliers (a point we will return to).

Mary is a 35 year old widow with 3 children and a Type 1 diabetic. Although Mary was aware of her diabetes, she was not at all prepared for her foot complications:

> I was checking my foot, and I found something like as if I am burnt. I decided not to pierce it. It was growing though I did not bother what might be the issue I just continued to put on gumboots to go to the garden (field). But it just worsened. I asked people and they told me it's septic arthritis and gave me some medicine. I then went to Harugongo (private clinic) and asked him before treating it to first check my sugar level. He told me I have high sugar levels and gave me some treatment and I gave him 30,000 shillings. I went to inquire from a certain lady whom I knew was also suffering from diabetes and had foot problems, and she told me to go to Nyantaboma Health centre III every Wednesday where they work on diabetic patients. I went there but they told me they can't manage my situation that I should go to Buhinga [FPRRH]. I went home and packed my things to go there. I was admitted to surgical ward and given treatment though the pain in the foot wasn't stopping, and it was becoming black. That was in June (2023). I was taken to scan and then x-ray. They operated my foot and removed that thing that looked as if I was burnt, and I was discharged. When I went to nurse the wound where they had operated, another toenail got the same issue and was turning black. It affected another toenail that same week. I waited but the wound under my foot had fluids and was really paining. I went back to hospital in July, and they decided to cut off my leg. I was asked for 100,000UGS. When I came back, they asked me for 250,000UGS to cut off my leg. I was buying medicine from a pharmacy to take care of my wound when I was discharged. The first medicine was 100,000UGS. I took it for two months. I had to sell most of my things to buy the medicine. In total I spent 3mUGS. (54)

Mary explains the impact of these costs. At present all her 3 children go to school, '*[but] I am a sole carer, and I don't know how it will go next term after me being in this position because I don't have any sponsors*'.

The cases discussed above illustrate the lack of effective referral systems with patients jumping around between sectors, negotiating long journeys and delays. They also evidence the late diagnosis of diabetes and the low levels of awareness of the relationship between diabetes, foot complications and amputation risk. Many cases started with a small wound or what respondents often described as burns (presumably ulcers). At this critical juncture nurses have a key role to play in identifying and managing diabetic wounds and spearheading amputation reduction strategies. Podiatry, a profession bridging wound care and orthotics in the UK, does not exist in East Africa. Although orthopaedic technologists have theoretical knowledge of 'Off-Loading' described by the International

Working Group of the Diabetic Foot as, 'the most important of multiple interventions needed to heal a neuropathic foot ulcer' (IWGDF, 2019; Sarfo-Kantanka, 2019; Zhang, 2017) this service does not exist.[3] Whilst nurses play a critical role in wound management, they lack training in the identification and management of pulmonary arterial disease or peripheral neuropathy that contribute to diabetic foot ulcer complications.

The interviews with health professionals echo these concerns around health systems failures. A British prosthetist who has spent a long time supporting physical rehabilitation services in Uganda commented that, '*There is no preventative medicine there and people either can't get treatment or by the time they get it their condition is so severe it is amputation anyway*' (T05).

One of the orthopaedic technologists interviewed echoed these concerns articulating a frustration with the lack of preventive services:

> As much as we want to provide rehabilitative services, we want to educate the community on how they can prevent disability. Some of the disabilities are happening because of how we do our work. If people can see what can cause disability or injury to them then they can prevent disability. If we work on problems earlier, we can prevent disability other than waiting to the very end when there is nothing much you can do. (D10)

A Ugandan orthopaedic technologist who runs a private clinic in Kampala was very aware of the relationship between diabetes and foot complications and the role that 'off-loading' and appropriate footwear can play in preventing and managing diabetic foot ulcers:

> the only challenge is materials on the market – to produce a good comfortable diabetic insole. People come looking for shoes and for those who can afford we order them from SHINE in Germany – they make diabetic shoes. [If] we had the materials the human resource is here to make these shoes. (D12)

Diabetic ulcers are only one of a variety of wounds that respondents identified as triggering their path to amputation. It is clear that respondents and often the health workers they have engaged with are not always clear about the diagnosis. We can only present their narratives as stated. Peter's

[3] Off-loading involves the manufacture of a bespoke insole designed to take the pressure off areas at high risk of ulceration.

case is a shocking example of the complex journeys transecting sectors, incurring catastrophic expenditure and resulting, in this case, in the loss of both legs. Peter is a retired civil servant now aged 82 and a double amputee. He lives about 13 km from FPRRH. Peter started to feel pain in one of his legs in 2015 and took painkillers. A year later he observed a 'small wound' near his ankle and started attending a nearby private clinic. The wound spread to the whole foot and, in 2017 he was admitted to FPRRH for wound dressing:

> They suspected diabetes, cancer, blood pressure, but all tests were negative. They said it must be gangrene, so they started treating me. I spent one week in the ordinary ward using public toilets and sharing the ward with everyone but because I had a wound, I saw it dangerous to be there because I would get other infection from the public, so I decided to go to the private wing where you get a self-contained room and are treated alone. They charged me 55,000 UGS (£11) per night for a room. I had to buy drugs from the hospital pharmacy and spent there 2 months and a lot of money but still the wound could not heal only spreading. I accepted the proposal to be amputated above the knee and spent another month there. But as I was ready for discharge, I developed a small burn on the other leg. I told the doctors about it, but they said don't worry you will be fine; it was small and reddish, and I was experiencing some heat there.

He returned home but, '*the burn had become a wound and was spreading, so I had to be admitted again. The doctors struggled to treat the wound with different drugs but no change at all and I was transferred to Mulago National Referral Hospital. They discovered my blood pressure was high, so they were treating the blood pressure and gangrene. They transferred me to Kiruddu National Referral Hospital in Entebbe.*[4] *Kiruddu asked me to have a CT*[5] *scan at Kampala International Hospital which is a private hospital because in Kiruddu they did not have this scan and the one at Mulago was not working. I brought the results to Kiruddu Hospital, and they said this is a heart problem and transferred me to Mulago Heart Institute (a specialist Unit attached to the hospital but which charges patients).*[6] Peter spent 2 weeks at Mulago Heart Institute where they told him that

[4] Kiruddu is linked to Mulago and specialises in cardiology.

[5] A computed tomography scan (CT scan) is a medical imaging technique used to obtain detailed internal images of the body.

[6] See Footnote 8 in Chapter 2.

his condition was complicated, and advised him to fly out to India or South Africa for more advanced treatment:

> They told me I would need 200mUGS (£43,000) and asked if I had insurance. I said no, so they asked, 'do you have some properties?' I said yes, and they gave me two weeks to go back and sell everything and report back as they prepare my flight to India for me and one caretaker. I came back home and saw my children. By then I was in my late 60's. Should I now sell the properties I have just for treatment? I had even sold much to reach where I was. I said no I cannot leave my children with nothing. Let me start using herbalists. I did not go back to Mulago Heart Institute. I started using the herbs from home but no change, the wound could not heal, I came back here to FPRRH, I was ready to be amputated because I knew that was the only solution. After one month when I saw the doctors were reluctant, I asked to be discharged and went to Virika Hospital (PNFP in Fort Portal). The same day the doctor took me to theatre and removed some bones that were rotting and thought maybe I could heal but it did not so eventually the doctor amputated my second leg exactly a year after the first. I spent 5 weeks in Virika. I am treating high blood pressure now. They prescribed three types. I am only using amlodipine tablets, and it is expensive, a strip of (10) ten tablets are 4,000UGS (£80p) and I have to take one every day so I could not manage all the 3 three types at once, and the other types were more expensive. Ooooh my friend, it was a lot of money that I can't even think of, because I sold all the cows I had and now have nothing, all these Hospitals I went to was charging me a lot of money for drugs. Virika charged me 500,000UGS (£107) for amputation only. FPRRH Private Ward charged me 700,000 (£150) for amputation. The CCT scan at Kampala International Hospital was 700,000 (£150). The heart Institute in Mulago Hospital charged me 450,000UGS (£96) per night in a general ward. Add all the transport that I used, my friend I spent a lot of money. (10)

Peter's case further illustrates the complex journeys patients make, and the costs involved. The decision to access private care in the first instance was Peter's reflecting his awareness of the risks of healthcare acquired infection. His subsequent referrals involved specialist facilities that form part of the national referral system but operate on a fee-paying basis and payments for services that were not available in the public sector. The proposal for him to travel to India is not unusual in Uganda but on this occasion, he made his own decision about the costs involved. Resorting to herbal remedies as a last resort is also quite common. Having exhausted all

of his resources Peter is left unable to afford the costs of basic medication to manage his hypertension.

We have referred (above) to some of the human resource management issues that have impacted our sample particularly the peripatetic nature of doctors, employed by the UMoH but jumping between facilities to treat patients privately. Annet's story illustrates the delays this type of behaviour causes to patients. Annet was 6 years old and living in Kyenjojo when she first noticed a wound on her leg:

> I got a pimple on my leg when I scratched it became a wound and spread all over the leg.[7] I was taken to FPRRH where I stayed for 4 years. Every time one side heals the other side gets affected too. I got crippled. My parents decided to take me to Kampala. We went to different hospitals like Mulago, but they did not treat us. They kept on telling us to come the following day and we got tired of going there without being helped. A person told us there is a doctor who treats skin in Lubaga Hospital. He told us to choose the hospital we want him to treat us from. We made an appointment and went to Kibuli hospital as he was also working from there. He said that the problem was skin ulcers. I stayed in Kampala for 3 months for skin grafting but the wound came back covering the whole leg and I was amputated. (37)

This case illustrates the sheer complexity of distinguishing private from public services in the Ugandan health system—or assuming that accessing public care is free. The public in Uganda expect to be charged in public facilities whether they are treated by government employees or not.

We referred (above) to the interplay of traditional therapies (including the use of herbs, witchdoctors, and bone-healers) with modern healthcare. Six respondents spoke of using local herbs at some point. Two of these only used herbs (both diabetic cases). The other four cases that cited use of herbs all combined this with witchcraft. Seven respondents reported using witchcraft at some stage and five, accessing local 'bone-healers'.[8] One respondent accessed both bone-healers and witchcraft. We

[7] Presumably cellulitis.

[8] Bone-healers are similar is some respects to Traditional Birth Attendants in that they lack formal qualifications but may have extensive hands-on experiential learning of managing bone fractures. For information see Bone setting: Treating fractures traditionally | Monitor (https://www.monitor.co.ug/uganda/magazines/life/bonesetting-treating-fractures-traditionally-1667070).

saw how, in the previous chapter, some patients chose to use traditional bone healers. Wedam and Amoah (2017) describe Traditional Bone-Setting (TBS) as 'one of the oldest medical practices that numerous people in Africa patronise' and identify cost and 'fast rate recovery' as two key drivers of use. They conclude that, 'where allopathic medicine has failed, traditional bone setters have succeeded' and argue for the integration of this 'essential practice' into modern health systems (p. 23). Konadu-Yeboah et al. (2023) suggest that TBSs in India treat over 60% trauma cases and found that a large proportion of the population in Ghana use traditional bone-setting either solely or concurrently with orthodox treatment. Their study involved the testing of a training program to improve skills and facilitate greater integration in the formal health care system. A doctor interviewed in our study expressed his concern that accessing bone-healers reflected the costs of formal care and, in some cases, patients were actively deceived into believing that the bone-healer could competently resolve their problems (Table 3.1):

> Most of the people in this area are down in their villages suffering going to bone healers. Somebody can get an injury, and you tell them what they need to get better, but they cannot afford it. The next thing you hear is that they have gone to a bone healer who claims he can fix the bones at 10,000UGS (£2). The bone healers just keep touching the limb deceiving the client that they will get better. (HW1)

Witchcraft and Wounds

The following section focuses on the seven cases that explicitly mentioned witchcraft in their wound care journey. Sadiki was living in Kampala in 2022 when he developed, 'a small sore' on his big toe:

> The sore progressed over two weeks to involve the entire foot. The whole foot became swollen and dripped with liquid. At first, the foot was very painful. A friend visited and advised me to go to hospital. I decided to go to Butabika referral hospital's private wing. Somebody assessed me and gave me some pain relief tablets. Then she advised me to seek help elsewhere because she thought that my disease was spiritual. She told me that my disease was likely to be a result of witchcraft. I returned home in so much pain and did not return to any healthcare facility for some months. (41)

Table 3.1 Use of alternative health care

	Herbs	*Bone-Healers*	*Witchcraft*
07	x		
10	x		
41	x		x
39	x		x
38	x		x
21	x		x
55			x
51		x	x
15			x
46		x	
12		x	
25		x	
03		x	
Totals			
13	6	5	7

It is unclear why Sadiki chose to access Butabika Hospital in the first instance. Butabika is the National Referral Hospital for Mental Health in Kampala[9] or why he accessed the private ward. It is interesting to note that he suggests it was a qualified nurse who tried to persuade him to turn to witchcraft. Sadiki did not immediately act on this advice though but returned home without any treatment for some months:

> My situation got worse by the day and my leg turned black up until the knee. What scared me most was that maggots were falling out of my leg. Colleagues from work suggested that I visit a witch doctor for help. We visited a well-known traditional healer. I was in so much pain and distress and would do anything that people suggested. I do not have many friends and when they suggested I try the witch doctor, I agreed. The nurse also hinted at the fact that my disease was caused by witchcraft and could only be sorted in a similar manner. When we arrived at the shrine in Kasokoso near Kampala[10] we were asked to enter and sit in a small grass-thatched house. The whole floor was covered with fetishes and dry grass. I sat between the witch doctor and my colleague because I was in

[9] www.butabikahospital.go.ug.

[10] Kasokoso is a large slum area near Kampala populated by the Acholi ethnic group displaced by the Lord's Resistance Army insurgency in Northern Uganda.

fear of what could happen. The entire room was pitch-black because the door was closed. Then the witch doctor called the spirits of the ancestors. Immediately, I heard a loud thud on the roof of the hut and strange noises descended to the centre of the hut.
Q. Are you sure the noises were not made by the witch doctor?
No, they were different with many talking at the same time. He was seated next to me, and I made sure that I listened to what was going on. I had rested my sick leg on the pillar in the centre of the hut. The voice of the ancestors told me to stretch my hand out and not be afraid. When I stretched my hand, a hand touched my hand. This hand was different because it felt smooth, like a baby's hand. The voice told me that I was bewitched in error.
Q. What do you mean?
That the witchcraft was conjured by a woman against another woman [co-wife] with the intention of killing the victim, but I unknowingly jumped over the fetishes and got sick in the process. The voice gave instructions on how to treat my leg. The spirits of the ancestors ascended through the roof of the hut. I saw a strange fire burning in the air during their departure.

At this point, this desperate and impressionable man clearly believed the witchcraft 'story'. What happened next, however, was a form of rudimentary and potentially harmful 'surgery':

The witch doctor and his wife took me outside the shrine and asked me to buy 2 new razor blades and a needle. He donned rubber gloves like the ones used in hospitals and cleaned the skin over my foot. He lifted the skin over my foot [dorsal skin] with a needle and made a clean cut around the entire foot. He then made another cut from my second toe towards the centre of the foot. Then, they peeled the whole skin away. I felt no pain and he did not give me any pain medication prior to the 'surgery'. He washed the foot in a red concoction of herbs [leaves and stem cuttings] boiled in water. He told me not to cover the wound and discharged me home. He asked for 200,000 shillings but I only had 100,000 shillings. He told me to bring the balance when I get it. I returned home but the leg got worse by the day. I could feel the maggots deep in the long bone [he points to the tibia of the left leg]. I would raise the leg for some minutes and then shake the maggots out after resting it on the floor. I decided to leave Kampala and return home to Masindi (220km north of Kampala).
Q: Why did you not go to the hospital?

> I don't know why. I think my mind was blocked from thinking about it. I honestly cannot give you a straight answer. I was suffering but never got the courage to go to the hospital or even seek professional medical help.
> Q: Why did you return to Masindi?
> I thought I was going to die. I honestly lived each day hoping that I would die in a few days. I lost a lot of weight. I had run out of funds to support my son and myself in the city. I went to a private clinic in the town and a nurse gave me a tube which I applied to the holes and the leg started drying completely. The powder in the tube killed the maggots and I felt better. A gentleman from Kampala visited one of my acquaintances and sympathised with me. He asked me to get an attendant to care for me while in hospital and took me to Lacor (PNFP) hospital in Gulu. The doctors took good care of me.
> Q: Why did they take you to Lacor hospital?
> I am not sure. Perhaps the person who paid for my treatment preferred that facility. I had no objections because I was too sick to refuse and had no money to object. I just wanted them to take the leg off. The gentleman paid all the money because I was too poor to pay.

The case illustrates the costs associated with witchcraft and the delays this caused although the respondent appeared to get some comfort from the engagement and clearly believed in the approach. At no point did Sadiki attempt to access public healthcare despite his lack of resource.

Vincent lives in Kyegegwa District. He was only 10 when his foot got infected, and he believed and still does believe that this was due to witchcraft. His case shows complex health seeking behaviour such that he wasn't actually amputated until the age of 21:

> My leg was amputated when I was 21 years. When the leg got infected, I dropped out of school. I spent many years at home. They first treated my leg locally using local herbs. They also performed traditional ritual ceremonies to try and treat the leg. Later, when they saw that the situation was worsening, they decided to take me to the hospital. The rituals were to first deal with the effects of the witchcraft [the medicine the old man had used to do the witchcraft] before treating the wound. If they had not done that first, I would have died. (39)

Vincent expresses a strong belief that, rather than delaying his treatment and potentially saving his leg, the witchcraft saved his life. When he did decide to access a public health centre near his home, he was immediately referred to the National Referral Hospital in Kampala for amputation.

Several cases referred to accessing spiritual advice/healing. In some cases, they referred specifically to visiting 'Bisaka'. Bisaka, a self-proclaimed Ugandan God and founder of the Faith of Unity Movement lived until his death in 2021 in Kagadi District, Uganda.[11] Kakurilemu comes from Kagadi District. She believes that her amputation can be tracked back to incorrect injections of benzocaine during a pregnancy which caused paralysis. She initially approached a local private clinic and was advised to go Kagadi town to a better private clinic where they suggested amputation, but she refused: '*Remember I was pregnant. Immediately after he discharged me, I did not go home, I went to (itambiro*[12]*) that's the church of our religion and that's where our god (Bisaka) lives. I went there and talked to our god, and he told me I was late I would not have reached to such a situation if I went to him first. He told me to pound garlic and wrap it in a cloth and use it to massage the leg so the concentration of the medicine will be at one place. I went immediately home and bought garlic. But in 2 days my leg started rotting so I went to Saint Ambrose (missionary) Clinic in Kagadi. They referred me to FPRRH and 1 week later I was amputated*' (15).

In this case critical delays occurred prior to accessing spiritual healing. However, an interview with a doctor working in nearby private hospital expressed concern that this behaviour can cause critical delays:

> We have the Itambiro here. We have the only African god here. There are believers who believe he can heal any disease, and I think the district health department has not done enough to bring him on board as a stakeholder to show him that there are some cases that we can manage other than spiritualising everything. You find someone succumbs to an illness that is manageable. Sometimes they end up coming very late and they can only get palliative care. Some other patients who have been sent home due to advanced illness and cannot be managed go there as the very last resort. They get the holy water. Even more mainstream Christian sects like pastors and Anglican groups keep patients there in their churches and they delay yet the disease is progressing. Now if the patient has operable breast cancer but you find the patient laying there depending on prayers to Mary. Others go there as a last resort. It is a mixture of issues. For example, if the patient has been told to go to Mulago and they do not have the money to go

[11] It is interesting to note that Bisaka died in a private hospital in Kenya following treatment for diabetes and high blood pressure (Daily Monitor Jan 26, 2021).

[12] https://world-religions.info/faith-of-unity-church/.

> there, or the government facility cannot provide the service free of charge, the next step is to turn to God. (HW1)

This respondent identifies various points at which patients may seek access to spiritual healing. In some cases, this leads to critical delays allowing conditions to progress and may reflect the costs of accessing formal public or private services (as a last resort). In others, spiritual healing may play an important role in palliative care where other options are exhausted. It is interesting to note his proposal that rather than denying such support the District Health Authorities should consider how to integrate this approach to healthcare within wider structures.

Mumbejja describes how he got an infection of his leg locally known as 'ettalo'. The term ettalo is explained by a national newspaper reporting the case of a 12 year old boy. In addition to the catastrophic expenditures incurred in navigating the health system the mother reported the reaction of her friends and neighbours: '*Our neighbours kept telling me it was witchcraft locally known as 'ettalo' and would not heal in a hospital. In our culture, most swellings of the feet point to witchcraft*' (38).[13]

Mumbejja initially try local herbs to treat his infected leg but did not himself access witchcraft. What is interesting about his case is how people in the local community responded to his illness and amputation and the stigma associated with it:

> Many fear me. Those who fear me ask why I got that sickness. They assume that it was caused by witchcraft. It is different to live with somebody who has had a disability from a young age but for somebody like me to lose a leg in less than a month, it is difficult for most people to wrap their minds around it. Others asked me to investigate the reasons why I got sick and lost a leg because they suspect it was witchcraft. I decided not to seek such answers because I wanted peace of mind. I am afraid that if I get to know that somebody wished to kill me my children would get angry and try to get even with that person. If my children hurt a person they suspect of witchcraft, I am afraid they would be imprisoned. I do not want conflict and want to keep my children safe. Investigating witchcraft means that I would need a lot of money to give to the witch doctor or spiritualist which money I could spend on taking care of my children. I do not wish to pollute my mind with such things because I want to move on with my

[13] https://www.newvision.co.ug/news/1338897/bone-infection-tiny-boil-costs-leg.

> life. I cannot get my leg back. I refused to get involved in investigating the reasons behind my sickness.

The last case cited here illustrates the sheer complexity of the Ugandan health system and the complex negotiations that patients make in trying to manage their conditions. Michael's case is included in this section although his amputation journey was originally triggered by an accident when a tree fell on him whilst playing at school. It was 10 years before Michael's leg was amputated. Michael is now 27, has 2 wives and 3 children and makes his living selling chapattis. Following the accident Michael was immediately taken to the nearest Public Referral Hospital (Hoima) where they attempted to manage his fractures. Michael explains how his father had to 'pay for everything—even the plaster'. Unable to afford the costs of in-patient care they returned home taking personal responsibility for wound dressing. Once home they engaged a local 'bone-healer' attached to Kagadi Public Health Centre (IV). Advised by the health facility that he would need long term care, and they were unable to admit him as an in-patient he took their advice, and his father rented a room for him near the clinic for a period of 2 years during which time he continued to pay the bone-healer for care. After 2 years he returned home. 9 years later his wound began to irritate, and he returned to Kagadi Health Centre and was advised by a doctor there that his leg was infected, and he should have an amputation. In common with many cases Michael urged the doctor to try to save the limb, so he had an operation to clean the wound. The doctor agreed, 'if you have money' he would try. After 2 weeks he was discharged home. But again 2 years later his leg was in pain. At this point he felt he had been the victim of witchcraft: '*I was thinking could I have jumped over witchcraft, so I called the people who pray, and they prayed*' (51). He then met a doctor at a funeral, who sold him some drugs, but he failed to get better, so he visited his local clinic in his village (Rwenkende) and was advised there by a nurse he trusted to return to the doctor at Kagadi Health Centre. The doctor advised him again to be amputated but told him they lacked the instruments and to go to the national referral Hospital in Kampala. Concerned about the costs this would involve Michael pleaded with the doctor to be allowed to purchase the necessary instruments and was asked for 1,500,000 UGS (£320). He sold some land and found the funds but as soon as he had paid the doctor his leg worsened, and he was amputated at Kagadi Health Centre. The interviewer expressed surprise that this was possible at this level of facility

(which do not normally conduct amputations) but was told: 'There's a doctor who does amputation even he can amputate arms'. Following discharge, the doctor visited him every day for 3 weeks to manage the wound. Michael estimated that he had incurred costs of around 7mUGS (£1500) including his care at Hoima hospital, Kagadi health centre and local healers but excluding his rent during his stay.

To summarise this case, Michael did first access a Regional Referral Hospital (in line with Ugandan protocols). This, however, involved punitive costs resulting in his father resorting to cheaper but very long-term support from a bone-healer which also required his father to pay rent for 2 years. When he subsequently sought surgery a doctor in the public facility asked him for money to pay. And 9 years later when he accessed the facility again, he was advised that it lacked the equipment and that he should go to the national referral hospital. Michael sold his land to raise funds for an operation that is not usually performed in a Health Centre. Given that the doctor subsequently made home visits we can be sure that this took place on a private basis. Michael's case illustrates the impact that major limb damage has on an individual and their family and the catastrophic expenditure incurred often over a very long period of time culminating in amputation. By the time the person is able to even consider accessing prosthetic services their access to finances is entirely exhausted. This provides the context which frames the subject of the following chapter on patients' experiences of accessing rehabilitation.

Conclusions

This chapter has described the experiences of that group of respondents whose limb loss arose from some form of long-term chronic condition. It illustrates the lack of awareness of both the conditions themselves, and the amputation risk associated with these both on the part of individuals but also many health workers. Echoing the findings of Chapter 2 we see the impact of Type 1 and Type 3 delays: awareness and health seeking behaviour and quality of care respectively. Type 3 delays extend over meandering spatial and temporal journeys and between public and private sectors. They also involve catastrophic health expenditures impacting family budgets over extensive periods of time. These experiences are likely to grow exponentially as the impact of non-communicable diseases and particularly diabetes and hypertension begin to undermine the foundations of an already resource-starved and inadequate health system. They

also underline the need to embrace and integrate preventive health care within more devolved community-based systems to manage these conditions in order to reduce amputation risk and the impact this has on individuals, families and the health system.

CHAPTER 4

Accessing Prosthetic Services in Contexts of Donor-Dependency

Abstract This chapter addresses the second stage in patient journeys post-amputation to rehabilitation. It describes the status of rehabilitation services for people with major Limb Loss in Uganda prior to the complex intervention. It outlines some of the damaging impacts of donorism in a country where rehabilitation is almost entirely dependent on the support of foreigners and Overseas development Assistance and the prohibitive costs that restrict access to rehabilitation services for the majority.

Keywords Donor/donations/donorism · Outreaches · Private not for profit · Public private partnership · Universal Health Coverage

Introduction

The concept of a Low- and Middle-Income Country (LMIC) tends to over-characterise countries as generically poor rather than riven with and nourishing inequality. Harris refers to the almost 'natural' tendency in global health, to dichotomise and generate binary categorisations; a tendency he contends reduces opportunities for frugal innovation (2024: 3). Uganda is a country of extremes; extreme wealth sits alongside extreme poverty. Recognition of this relationship is not only a cause for dismay; it also signals opportunity in terms of economic development.

L. Ackers et al., *Delivering Universal Health Care to People with Major Limb Loss or Damage in Low and Middle Income Countries*,
https://doi.org/10.1007/978-3-031-85423-1_4

Bakwatanisa et al. (2016) describe healthcare globally as 'a public–private enterprise' and Uganda as a country with 'pockets of luxury' (and abject poverty) that are hardly distinguishable from North America or Western Europe. Their paper, on access to and affordability of biomaterials in Uganda, underlines the importance of viewing all health systems as mixed economies (Ackers-Johnson & Ackers, 2016). In the absence of any needs-based, universal, access to publicly funded prosthetic services, patients are left to negotiate a complex and largely opaque web of fee-paying 'options'.

Sekyonda et al.'s (2018) paper on supply chains for orthopaedic implants presents a unique lens on procurement processes spanning the mixed economy of healthcare in Uganda. The authors describe how their study was prompted by 'two confounding observations […]. First, although services in public healthcare institutions are ostensibly free of charge, this is almost never the case when surgery is involved. Second, was the ambiguous nature of the negotiations between patients, doctors, private vendors, donating entities, the government, and non-governmental organizations (NGOs) that determine access to medical implants' (2018: 1). The authors describe three alternative procurement pathways for implant devices. A 'Donations' pathway sits alongside the 'Negotiated Patient Prescription' or 'Hawker' pathway in public facilities, whilst the 'Physician Mediated Procurement Pathway' describes procurement processes in the private for- and not-for profit sectors. The situation, as described mirrors the prosthetic service landscape. Two key differences, in a rehabilitation context, are that orthopaedic implants are utilised in operating theatres (so in-patient settings) whereas prosthetic services can (theoretically) be provided in more diverse settings—even under a Mango Tree or outreach tent. While there are prestigious private hospitals in Kampala none of these have integrated physical rehabilitation units. Instead, they engage with individual orthopaedic technologists who work in a more peripatetic fashion either from the public workshops or their private workshops.

Sekyonda et al. describe the 'Donations Pathway' (Fig. 4.1) where implants are 'provided through collaborative partnerships' (2018: 1). They describe how, 'visiting surgeons from mostly Western institutions often request implant donations from established overseas companies to be used on short-term medical missions […] with patients receiving them on a first-come first served basis depending on supply (2018: 3).

Fig. 4.1 The Donations Pathway (*Source* Sekyonda et al., 2018: 3)

'Pathway 3' (Hospital or Physician Mediated Procurement in Private Hospitals) captures access to implants in the private sector conflating private (for-profit) and private (not-for-profit) hospitals (Fig. 4.2). This conflation makes some sense in the Ugandan context distinguishing this broad sector from the public sector (Pathway 2) where patients are not permitted (in theory at least) to fund materials through out-of-pocket expenditure. We have also noted (above) an important distinction between implants and prosthetic devices in that the former can only be fitted in a formal institutional (hospital) setting and by qualified surgeons. In this context, Sekyonda et al. describe the scenario in private hospitals where, '[neither the hospital nor] the patient plays a direct role […] the surgeon negotiates the price and purchases the implant on behalf of the patient [and] the patient is responsible for the entire cost' (p. 7):

This chapter describes respondents' experiences of accessing physical rehabilitation services post-amputation. It is important to remember that all of the sample did eventually access free public services at Fort Portal Regional Referral Hospital (FPRRH). This distinguishes them from the overwhelming majority of people suffering major limb loss in Uganda. The life-history approach to the interviews, however, enabled us to capture experiences *prior to* the intervention. This includes a cohort of secondary users (those who had previously accessed devices) and those who were unable to access services in the past. Respondents' stories

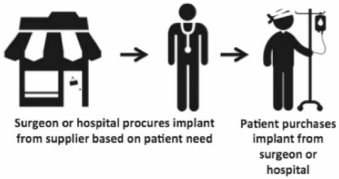

Fig. 4.2 The hospital or Physician Mediated Procurement Pathway in private hospitals (*Source* Sekyonda et al. 2018: 4)

are complemented with interviews with health workers and in-country researchers.

Understanding the Donor Pathway in Physical Rehabilitation Services

Although Sekyonda et al.'s model provides a very useful framework, inevitably the situation on the ground is more complex and sectors interact in complex and opaque ways. Evidence from the interviews has identified a number of different forms of donor engagement:

1. The 'Outreach' Approach

   A popular approach by donors is to incentivise orthopaedic technologists (including those employed by the UMoH) to deliver a population of clients through organised *outreach* activities for the provision of services by teams of visiting foreign professionals. In some cases, the service may also be provided on an outreach basis (at a camp or using private vehicles). In other cases, clients identified as part of organised outreach activities will then be funded to access the public workshops. There are variants on this approach which may include pre-training Ugandan technologists in a specific technology and funding them to provide the service either peripatetically or in workshops.

   In other contexts, outreach activities are organised by foreign or Ugandan donors and simply involve the distribution of devices with no professional involvement. For example, the lead, usually a charismatic local leader or politician accesses second hand devices (and wheelchairs) to distribute. This approach was used recently in Fort Portal. A local (Ugandan) NGO, with no experience in physical rehabilitation, received funds from an international donor to fit 50 prosthetic hands in one day. The hands were of very poor quality and no discussion took place about the devices or the lack of any rehabilitation process or subsequent repairs.
2. One-Off funding of Public or Private Workshops.

   This approach may involve the provision and fitting of devices and/or materials for defined numbers of users in public workshops (with or without staff incentives). For example, a 'donor' might distribute funds for 10–50 prosthetic limbs and delegate service

provision to a public workshop either providing the devices in-kind or requesting the technologists to procure. Accountability is typically very poor and corruption endemic with these approaches.

3. Personal 'sponsorship'

   It is common to see individuals brought to workshops by personal 'sponsors' to access services. Sponsorship may cover the costs of materials and/or travel and subsistence. For example, a foreigner attending a local church may see someone with limb loss and fund them to access a public or private workshop. It is also common for local Ugandans to fund forms of personal sponsorship perhaps covering travel to workshop or, in some cases, taking the amputee into their home to support them.

4. Inter-Organisational Partnerships

   Various partnerships exist with Not-For-Profit providers where the foreign partner raises funds for varying combinations of human resource, materials, equipment and travel/subsistence for users. This may include large PNFP hospitals or organisations in partnership with these. For example, a large charity such as the Rotary established a program over a defined time period which funds a prescriptive supply of prosthetic limbs sourced from an overseas supplier (ICRC or Jaipur).

   We have used the term 'partnership' here, but it is very common for foreign organisations to establish themselves as independent PNFP service-providers actively avoiding interaction with public services. This effectively creates a complex maze of parallel services of varying size and duration.

The first 3 'approaches' fall largely in line with Sekyonda et al.'s 'Donations Pathway' and will be discussed first. Approach 4 falls broadly within the institutional model described in Pathway 3 and is discussed in a later section.

Patient Experiences of Accessing Services Through the Donations Pathway

As we have noted, the Ugandan Ministry of Health fund orthopaedic technologists to work in 13 orthopaedic workshops located in regionally distributed referral hospitals but in the absence of any core public

funding for equipment or materials for device manufacture or repair. In this context, the provision of free services[1] is dependent on external funding, primarily from overseas donors for service delivery. The interviews demonstrate how this combination of public funding (for staff) and private funding for materials (and/or travel) is articulated to shape service delivery.

A specific manifestation of the 'humanitarian legacy' referred to in Chapter 2 is the practice of sending materials and components to LMICs. This often includes whole devices (prosthetic limbs) or 'kits'. The rationale for 'whole limb donation' reflects a pragmatic response to the need for simplistic (and corruption-proof) audit mechanisms (number of legs distributed) and uncertainty about supply chains and procurement processes (quality and costs) in-country. Sekyonda et al. reported a preference on the part of the foreign surgeons for implants from the US and Germany 'primarily based on reputation' and perceptions (and/or experiences) of using implants from India (2018: 5). Drawing on the humanitarian legacy, it also reflects assumptions about the lack of *proximate* health worker expertise. Humanitarian emergencies and conflict are playing a decreasing role in limb loss in Uganda overtaken by patterns of non-communicable disease, personal violence and road traffic accidents. This creates the opportunity and need for greater forward planning, service integration and distribution. Harnessing existing human resource is critical to this.

Managing Human Resource in the Context of Donorism

Chapter 1 rehearsed some of the weaknesses identified, primarily by foreign 'experts' in the Ugandan health system that require action in order to improve rehabilitation services. We challenged the emphasis on human resource deficit arguing that the task-shifted Ugandan model focused on generalist orthopaedic technologist is actually fit-for-purpose and has real potential for frugal innovation in high income settings. We also noted the current over-supply of orthopaedic technologists with

[1] Users are able to pay for a range of private services through health 'tourism' (travelling overseas) or out-of-pocket expenses. The Ugandan Government prohibits payment for public services.

many struggling to secure employment. It is absolutely clear that a significant commitment to the provision of infrastructure, equipment and materials, on the part of the Ugandan Ministry of Health, would create the need for more staff to meet patient demand. Until that is the case, we would challenge the emphasis in the ATScale Report on the 'lack of educated and informed workforce' (2021: 3) in the Ugandan context and argue that human resource either in the form of volume or capability is not the primary barrier to change.[2]

Harkins et al. touch on the issue of task-shifting—implicitly—in their discussion of the WHO-advocated Community-Based Rehabilitation (CBR) model. They reference dissenting critiques that this model (and its task-shifting approach), 'delegates highly skilled rehabilitation treatment to cheap uneducated locals without proper training or sufficient input from medical professionals'. We would concur with their conclusion that 'a workforce of well-trained local prosthetic and orthotic professionals must be employed' (2013: 360) but differ in our contention that this workforce does exist in the Ugandan context and could be deployed to strengthen rehabilitation hubs in the regional referral hospitals.

The assumption that the capability of existing human resource is a barrier to service delivery is in part responsible for donor approaches to supplies. Donors generally fail to engage actively with skilled local professionals when making decisions about service development, choice of technologies and materials. We have found that orthopaedic technologists have a sound background knowledge of technologies and a remarkable propensity for innovation and 'making do' with random and disparate materials combining components and technologies. In that context it is disappointing to see how most donors fail to actively engage with technologists when making procurement decisions and planning interventions. Gavette et al., with reference to high income countries, point to the limitations of technological innovation conducted without the active engagement of users and clinicians (2024: 2). The authors propose the introduction of a 'Technology Acceptance Model' to ensure innovations in prosthetic design are both desirable and useful to users. Arguably the same needs to happen in relation to health professionals not only

[2] There are an estimated 500 orthopaedic technicians across Uganda (Mulindwa et al., 2023; UMoH, 2020), which is adequate coverage under the International Society of Prosthetic and Orthotics guidelines, but it's unknown what proportion work (to any extent) within the government sector.

in shaping relationships between researchers and users (as Gavette et al. argue) but also with professionals at that interface.

Rarely do foreign NGOs negotiate technologies or preferences in terms of materials with technologists. This issue emerged with some frequency in the interviews with technologists. One stakeholder with significant experience of co-developing rehabilitation solutions in Cambodia suggested that '*some foreign NGOs trial crap technology on poor people who won't answer back*' (R11). It isn't clear here whether he is referring to patients or technologists, but it is certainly the case that health professionals in Uganda find it hard to challenge the behaviour of donors for fear that supplies may dry up or they will irritate their managers.

A more typical comment is the one made below by a Ugandan distributor referring to the tendency of donors to bring their own supplies into the country. Not only does this undermine supply chains in-country, but it also cuts technologists out of decision-making. Concerns about this approach are summed up nicely by one respondent:

> Donors ship their own materials in directly to support their own service provision. (D04)

It is interesting to note the reference to 'their own' service provision here. Whilst this approach in part reflects the assumption of human resource deficit either in volume or skills terms (so it is the donor who provides the service), it also enables NGOs to circumvent the challenges of in-country supply chains.

Donors often send complete 'kits' including materials available on local markets such as Plaster of Paris and Velcro. An discussion with a prosthetist in Tanzania identified an individual UK-based philanthropist who supplies quantities of materials for the manufacture of laminated sockets. '*[She] supplies this all herself. I'm not sure where she buys it. Lamination is our preferred method*' (SH14).

K4C has a partnership with Mnazi-Moja hospital in Zanzibar is currently actively supporting bilateral knowledge transfer between teams in Uganda and Tanzania. This has stimulated discussion around the merits of different technologies for socket manufacture (comparing lamination, traditional draping and bubble draping). Each of these technologies draws on different supply chains. Achieving some consensus would facilitate bulk purchase and cost reduction. Patterns of donation steer the selection of technologies rather than any evidence-based analysis. When

probed further the prosthetist above (SH14) explained that she had never been exposed to bubble draping; her 'preference' seemed to reflect the availability of equipment and supplies as much as evidence-based selection.

There is a certain inevitability about this particularly when donors organise targeted training around their own choice of technologies rather than contributing to a more structured Continuing Professional Development approach guided by national professional associations. As one Ugandan researcher put it, '*The manufacturing techniques used are ones taught by prosthetists from the ICRC (International Red Cross)*' (R06).

Dickinson et al., with reference to the Cambodian context speak of a 'history of harm' caused by the direct application (by foreigners) of inappropriate technologies. They argue in favour of an 'appropriate technology' concept that takes account of the resources available in the local economy (2019: 2). In addition to concerns about access to materials they identify a 'worst-case outcome whereby well-meaning projects result in technologists replacing their traditional skills and becoming less competent at traditional service delivery should the donor commitment come to an end' (p. 5).

The concept of appropriate technology echoes the language of a much older concept of 'intermediate technology'. Harkins et al. note the reference to appropriate technology in their literature review of prosthetic and orthotic services in LMICs but conclude that there is no consensus on what this is.

On the one hand, papers suggested that imported devices from industrialised countries require regular maintenance and are not designed for the environment or lifestyle needs of disabled persons in LMICs (2013: 357). On the other hand, 'indigenous devices are often regarded as primitive' and may not meet user needs in terms of cosmetic finish.

The donation of materials has, perhaps unintentionally, determined the choice of technologies and impeded exposure to other options. When asked why they chose to supply the Jaipur (modular) leg system, one of the UK partners described the system as:

> easy to make, replace and maintain. There are too many different systems which don't share the same materials. If you were going to [give local technologists more choice] there would have to be a whole re-think in the clinics using the Jaipur system. (T05)

The funding in this case supported the purchase and direct import of 500 Jaipur limbs. When asked if he was able to play any role in the choice of technologies and materials the local technologist replied:

> No, I found everything in place. They shipped the machines and all the materials from India. I asked, is it possible to add another technology and the hospital management told me - with time. (T06)

Interestingly the PNFP facility supplying (only) Jaipur limbs has found it hard to achieve their targets reflecting both user preferences but also service charges imposed by the partner hospital.

The discussion above illustrates how donor decisions about technologies impact human resource in health systems where more comprehensive, nationally designed and accredited Continuing Professional Development programs are not in place. At present donors inadvertently drive technology excluding and disempowering local professionals. And this impacts demand in local markets and supply chains. Pazirandeh makes the interesting and quite critical point that, 'hardly any research covers the issue of sourcing in humanitarian networks' (2011: 363). She argues that the 'specific characteristics' of humanitarian aid have 'forced' a particular approach to sourcing. More specifically her review of the literature suggests that the emphasis on 'voluntary contributions of finance and labour' exclude the beneficiaries from any commercial transactions. She concludes that further research on sourcing in the humanitarian aid sector is required.

Knight et al., in the rather different context of energy policy in LMICs, argue that greater attention needs to be paid, not only to incentivising demand but also supply markets. They suggest that 'supply market research' has been neglected when clearly demand and supply work together. They show how supply-side market failure may trigger a 'vicious cycle' that blocks or constrains innovation adoption; 'uncertainties in [..] supply dampen, or prevent, the development of demand (2015: 167). The tendency of NGOs to make their own supply plans often specifically (and perhaps necessarily) designed to avoid local markets ultimately undermines the potential for national or regional supply chains.

Outreaches, Camps and the Numbers Game

'Outreach' interventions (as described above) are a prime and fundamentally unsustainable example of what Humble (2012) refers to as, 'a comforting myth' providing immediate gratification and accountability (of sorts) for short-term 'donors'. We referred (above) to the demand from donors for simplistic (and corruption-proof) audit mechanisms. Accountability and conditionality are critical to ensuring that ODA, particularly when it is funded through government revenues or charitable giving, is used efficiently and effectively. We have noted elsewhere how this creates resource silos impacting even access to life-saving antibiotics (Ackers et al., 2020). In an environment crippled by endemic corruption this has the unintended consequence of a growing obsession with quick-fix quantitative outcome measures (typically number of limbs distributed).

The apparently simple ability to 'count limbs' appears to be one of the factors stimulating donor interest in prosthetic devices. In practice, simple enumeration is easy to 'deliver' but it is rarely meaningful. Bouchard et al. report the presence of corruption 'at the worker, hospital and government levels in the forms of misappropriation of funds, theft of equipment, resale of drugs and medical devices, fraud and absenteeism' (2012: 1). The theft of materials and overcharging stifles the entire health system particularly in areas (such as prosthetics) where valuable commodities are involved. It also lends justification to 'numbers game' approaches. Achieving high volume objectives over short periods of time is often achieved through 'outreaches' or 'camps'. The unintentional consequences of this are described by a Ugandan technologist:

> International organizations are there but with specific interests. If you fail to meet targets in the numbers of patients fitted, funding becomes a problem. [One outreach] was funded by the Indian Association of Women in Uganda. They made announcements over the radio. Their target was to fit 500 limbs. They wanted their own (Indian) team to come – they paid their tickets, accommodation, and allowances. They came here for 40 days and fitted 500 clients. They had no time to train clients. They just took the limbs given them that very day with no training. It was just fit and go, fit and go. Some ended up not using their limbs or dumped their devices with us. They were uncomfortable. Most of them expressed dissatisfaction and wanted to know if we still had Legs For Africa components. As soon

> as we get them, we will invite them to come and change from the Indian type.
> Did [the donors] ask if you could provide the services yourselves?
> We could do it ourselves! We just don't have materials. (T19)

Bulk donation from overseas is commonly used in outreaches to save time and avoid having to engage with corrupt and expensive local procurement systems. The following case illustrates some of the unintended consequences of donorism. Mariam lost a leg at the age of 15 as a result of a land mine left behind in the war near Kasese in Western Uganda. Mariam describes her experience of receiving 10 devices over a period of 22 years:

> A lot of people from the Kasese area who had lost limbs who were brought by the Anti-Mines Network and Handicap International - organisations run by white donors - to where the Red Cross was giving free legs. I spent 2 years with [that limb] before it started getting damaged. It was shorter than my other leg because I was still growing. I heard a radio announcement calling people who need artificial legs to go to a local organisation in Kasese for help. That organisation sponsored my travel to Fort Portal to get a leg. After a certain time, another donor in Kasese took us to a place in Mukono to get limbs. It was a small workshop attached to a church run by white donors. I [also] went to get a leg at Mbarara University hospital. We spent two months waiting for the limbs. The white donor who took us there paid our transport and upkeep, but we got substandard work. We took the limbs and left disappointed. I only used that leg for two days and abandoned it. I [later] went to Mulago. There was a camp run by Indians who were giving free legs. The organisation sponsored our transport. When I arrived, the legs were fitted. It was not the same as I had experienced elsewhere. They took patients' measurements and picked an already made limb. You went home the same day. I took the leg home but did not use it much. (31)

Mariam's case illustrates the complex dynamics and 'potluck' approach to accessing donor-funded services. It also demonstrates the problem of treating rehabilitation as a 'one-time' event that can be dealt with through ad hoc donations. Such donations, particularly when there is no rehabilitation process, often result in the abandonment (and resource waste) she refers to. Gavette et al. (2024) with reference to prosthetic device use in high income settings cite evidence of very high levels of abandonment (44%) of even the most advanced devices. This may reflect a combination of discomfort, users being more independent without a prosthetic device

but also where user-training (rehabilitation) enabling users to adapt to their devices is overlooked. People's needs change over time and devices need repair and adaptation underlining the need for stronger relationships with more local and accessible public service infrastructures.

Joshua attended the Mulago outreach and also abandoned his device:

> My first experience was an outreach organised by Indian Women of Uganda. I did not practice with my leg at Mulago [but] tried to practice by myself at home. I used it for a week and the foot broke. I didn't return as the donors had left. It was not useful. The parts were weak. (44)

Fred also attended this camp travelling over 300 km:

> They charged me 1.8mUGS (£385) but that wasn't the [device] I deserved. I trained for only one day. This leg is longer than the other and causing an imbalance. They just went back to the workshop and pretended that they've done some work and brought it back. They were in a rush because they were remaining some few days to travel back to India. They didn't give patients enough time. (49)

This case is interesting as the interviews with technologists suggested that this camp provided free limbs and yet the respondent describes paying. A different approach to outreach involves funding and providing transport for Ugandan technologists to go out into local communities to locate clients and either assess them in situ or conduct follow-up work with patients who previously attended camps. A technologist explains his concerns about this approach and preference for some kind of transport facilitation to bring patients into the workshops:

> We don't have addresses [in Uganda] so they say, 'it's under the mango tree'. When you get there, there are many mango trees. We would rather say – when donors come – instead of giving us a million [shillings] to go and spend lots of time trying to find lots of people you bring them in here. We can use the same money to treat a lot more people. They will come if we refund the transport. (T01)

Responding to another problem caused by donors which can result in overwhelming workloads and extensive patient delays (which also puts patients off attending services) he proposes a more structured appointment system:

> If you say 'come tomorrow the transport is there' they will all arrive at the same time, so I have started trying to implement appointments. (T01)

He also describes a smaller scale approach, '*where an organisation wanting to support 10 people with disabilities will approach us. We get quotations and if they are able to sponsor, we purchase things*' (T01).

This approach appears more sustainable involving fewer cases. It also gives the local team the autonomy to purchase what they need and make their own professional decisions on device manufacture. Nevertheless, it remains focused on limited outcome measures. It is important to remember that these technologists are employed and paid by the Ministry of Health to run services in public workshops. When donors pull staff out of these workshops to run outreach programs, they have a major distorting effect on the public facilities which will often have to close to the public for that period.

Not all donations or outreaches are organised by foreigners. Some of the problems of donorism and outreaches are replicated by local Community-Based Organisations (CBOs). This type of outreach is often wrapped up in political campaigning supporting the types of clientelism described by Chabal and Daloz (1999: 39).

Outreach Organised by a Community-Based Organisation

The following technologist describes an event organised by a local community-based organisation, inviting people to come and receive assistive devices, including wheelchairs and prosthetics. The public were invited to come along to a local community facility:

> [The organiser] told us that she provides prostheses for patients that need them. My worry was that she does not know how to cast, she does no measurements. When she finds that somebody is missing a hand, she just provides a hand without prior assessment. So, I was wondering how this is done, how the treatment is done without measurements. The place was just one small room. (T05)

In this case, orthopaedic technologists at Knowledge For Change heard an announcement on the local radio inviting people with limb loss to attend an outreach. At this point no contact had been made with the

local orthopaedic workshop only about 1 km away. When the K4C team arrived, they were shocked to find a large number of people with no professional staff:

> Thirty people with different conditions, upper limb, lower limb needs etc. turned up. Some had come from far. The team had no professionals who could do that work. They did not know what to do. She could not handle them. (R12)

Outreach activities commonly form part of national or public occasions where dancing, music and political speeches take place alongside health education, blood donation and screening activities. These, essentially performative, events typically take place in tents in large public grounds and not at health facilities. By way of example one such event was organised by the Ministry of Gender, Labour and Social Development to Commemorate the International Day of Persons with Disabilities. Knowledge For Change received an invitation to the event with the specific request to, 'mobilise and distribute assistive devices to persons with different categories of disabilities'. As an organisation K4C supports health education and awareness raising activities in such situations but has resisted the temptation to deliver peripatetic health services as we firmly believe that patients should be encouraged to access public health systems to ensure respectful, holistic and long-term care.

Personal 'Sponsors'

In many of the cases above individual 'sponsors' (Approach 3 above) alerted respondents to the presence of camps and facilitated their access to them. In other cases, personal sponsorship enabled users to access public or private facilities, typically on a one-off basis. Ninsiima is a bilateral upper limb amputee whose case was discussed in Chapter 3. She talked of how her original devices funded by personal 'sponsors' failed almost as soon as she received them and, on both occasions, she was unable to access any follow-on care:

> 'The [device I got] from Mulago didn't work well and broke when I got home.
> Q: You didn't go back to get it repaired?
> No, the one we were contacting didn't answer his phone.

> (The trip to Tanzania) was paid for by a white man who found me in church. I stayed there for a month. In Tanzania they gave me a functional hand with strapping. I could put it on by myself, but it was heavy, and I have a damaged shoulder which swelled up badly.
> Q: How come you didn't know it hurt when you were in Tanzania before you came home?
> I thought maybe I'd get used to it and it would settle down.
> Q: Did anyone from Tanzania help once you were back in Uganda?
> I had no way to contact those people. That white man went back to his country.
> [She then told us 2 Chinese men gave her a device during a chance meeting at a Hotel in Kampala]
> How long have you had that device?
> 4 years
> Q: If you did need to repair it, what would you do?
> I don't know. I don't have their contacts' (37).
> Ninsiima later was fitted with a Koalaa device.[3]

All of the 'approaches' deployed above share, in varying degrees, some of the limitations of reliance on donations. These include the random and unpredictable quality of donations both in terms of financial arrangements and in-kind product supply, the temporal quality of interventions and prescribed client selection criteria.

Random and Unpredictable Donations

> Africa is becoming a dumping ground for donations. People are forgetting the actual patients. We see hundreds of thousands of limbs sent that are never used and when they are, they can cause more harm than good. (D09)

Sekyonda et al. cite respondents from the UMoH expressing concerns about the randomness of donations and call for clearer guidelines and policies on donated medical equipment: 'You cannot really tell who is donating, what is being donated, and how recent(ly) the donation came in' (2018: 5).

[3] Whilst she liked its appearance Ninsiima had developed real agility with her stumps and the device actually reduced her functionality. Ninsiima was not a participant in the Koaala study reported on in Chapter 7.

Smaller organisations or individual donors often rely on recycled second hand parts. Recycling is an increasingly important way of managing resources globally and mitigating the environmental damage of waste. Managing 'giving,' without undermining the altruistic spirit, is a key challenge in global health as individuals and organisations often believe they are doing the 'right thing'. We have noted elsewhere some of the damaging effects of this in the context of biomedical engineering (Ssekitoleko, 2013). One of the foreign stakeholders interviewed made the simple comment:

> We try and take stuff because we think it's easier and we're 'giving' something rather than thinking, 'are we giving the right thing'? (R02)

Another stakeholder referred to the problems he had seen with donated second-hand sockets:

> Many donated sockets are used without alteration which can result in further pathologies due to anatomical differences between the original user and the patient receiving the 'recycled' socket. [R08]

The use of donated sockets is not a problem we have witnessed during our research. In most cases where technologists lack access to the materials for socket manufacture the patient has to pay or go without. A much more common and inevitable problem with donated components, especially prosthetic hands and feet is the colour (B. M. Oldfrey et al., 2024).

> The colour of cosmetic covers and foot shells are predominantly Caucasian and not a correct colour match for Ugandan patients. This causes issues due to social stigma and discrimination. (R08)

The donation of recycled components is also often random and unpredictable making it hard for technologists to assemble complete devices:

> All components are from donations which means they are not always compatible systems. Relying on donations results in no guarantee of quality and a mix of components from different suppliers, so there is no consistency in approach for the team putting together the prosthetics. (R06)

The following researcher feels that the lack of coordination and compatibility leads to waste:

> There is a silo mentality. Each piece comes from a different donor and a lot goes unused. (R01)

One technologist/distributor comments on the impact of random 'giving' on service planning:

> It's been like this for a long time. Donors come and give you things and yet you are supposed to come up with a long-term plan. It's just giving. (D02)

It is easy to criticise donors for what seems like a misjudged approach. It is important to balance this with the exponential pressure on donors to extend their support to an ever-increasing number of recipient organisations. In such situations where there is so little support for rehabilitation services in LMIC health systems, managing expectations and justifying allocation decisions becomes a real responsibility. The unpredictability of recycled donations is also linked to delays:

> [They] sent further consignments, but they took a long time and what was received was unpredictable and random. (R06)

A similar point is made by one of Sekyonda et al.'s surgeon respondents who says, '*There is no definite frequency for the replenishment of donations; they are not as regular to be a dependable source*' (2018: 5). Urva et al. (2013) also refer to the importance of managing expectations to generate a realistic understanding of the ongoing rehabilitation challenges to prosthetic use. In the absence both of expectation management and time for rehabilitation support users, who often imagine a complete return to life as normal prior to amputation, will compound the risk of device abandonment and poor outcomes.

The Temporal Quality of Donorism

A well-rehearsed problem with reliance on overseas development assistance is its temporal quality with many projects funded for very short periods. As one funder leaves another may arrive leading to stop-start

funding and often a mix of technologies and approaches. This is a problem in all areas of health care including capacity-building projects. But it is a specific feature of rehabilitation interventions most of which are funded under humanitarian relief schemes where the assumption is that, once the emergency has gone away, normal systems will revert. The concept of an 'exit strategy' is often seen as essential to longer term sustainability in a 'before-and-after' intervention model. Whilst exit strategies have been encouraged (and sometimes required by funders) in order to avoid the kinds of dependency we have referred to, it is very simplistic to assume that short-term injections of support can become seamlessly integrated in what are highly dysfunctional, under-funded, health systems. Nowhere is this clearer than in rehabilitation services which are so poorly integrated in existing systems. One distributor describes his experience:

> The programs ended, and the partnership ceased. I think they had some issues with money. (D10)

A technologist makes a similar observation:

> The International Committee of the Red Cross was providing materials. The workshop was operating really efficiently, and we had lots of patients coming in. Then they completely pulled out. (T03)

Physical rehabilitation is, by definition, a continuous process. Ideally commencing with prevention programs and continuing through emergency or long-term care through to the provision and management of devices. This is very obvious with children who will need regular replacement of devices as they grow. It is also the case with many adults when the residual stump expands or shrinks. Rehabilitation is not a one-time, single-morbidity, event. Treating it as such inevitably leads to poor patient outcomes, device abandonment and waste. The impact of short term donorism was evident in the discussions with patients about repairs. It is common for donor interventions to only supply new devices and not anticipate future repairs or adjustments. For the sake of optimal publicity many donors also prioritise primary users (those who have not had a previous device). In the following case, the technologist described a project where patients had to cover the costs of any follow-up services:

> I did beneficiary feedback analysis and one of the issues that kept coming up was the patients were not coming in for repairs because the [facilities] don't have the money to pay for repairs. When you come for repair, you must pay from your own pocket. (D04)

Secondary users generally had very poor experiences of repairs. None reported accessing public orthopaedic workshops. Two respondents explained how the devices they were given by donors later needed repair. They had no choice, at that time, but to find their own solutions:

> My foot split after 10 years. The material back then was very strong. There is a metal around which the foot was moulded, and this is what remained. I cut two rubber slippers and put them together and wrapped these around the metallic component of the foot and fastened these with a rubber string. I cut the rubber slipper in the shape and size of my other normal foot to make myself an artificial foot. I made myself a leg which I have used for the past 8 years. I was a very strong man, but when my leg shrunk because of old age and the socket could no longer fit so I covered the stump with 3 sets of socks and added an extra piece of cloth to make up for the lost muscle mass. (2)
>
> I took good care of my first leg because it was a lifeline for me, a support for me to walk and meet my needs. Unfortunately, the pipe that connects the foot to the stump broke after 4 years. I asked [the workshop] if I could get another pipe but was told that they did not have any. I went home and became innovative: I used black rubber strips to secure the broken pipe, to keep it steady. I fastened the two pieces of pipe together and used my leg again. (42)

Donor 'Selection' and the Challenge to Universal Health Coverage

One of the inevitable impacts of external funding on services is the impact it has on access. NGOs have to compete for funding for their interventions and identification of specific groups deemed to be in greatest need or on the global political agenda inevitably shapes their approach. We have noted the interest in primary users. Many funding bodies encourage or require a focus on refugees without considering the impact of this in LMIC contexts. Refugees doubtless face specific forms of poverty and social exclusion. But in societies where there is no public welfare

safety net for citizens and where external partners make such a significant contribution to public welfare this approach can, itself, constitute a form of discrimination. It also puts local health workers in a very difficult ethical position. During an early visit to FPRRH we were surprised to find only Congolese refugees at the workshop receiving free transport, services and support with subsistence. During a subsequent visit when this funding stream had disappeared only a few Ugandans were present. A K4C volunteer based at the workshop made the following observation:

> The UN funding for Congolese refugees is higher than the funding issued by the government for the treatment of nationals. This puts a strain on staffing levels and deprioritises the treatment of Ugandans creating longer waiting times. It also doesn't cover the whole cost of the rehabilitation process, only the device so the cost of rehabilitation for refugee patients is absorbed by very limited government funding. (R06)

This legacy continues. A technologist explained in a recent meeting[4] that the public Gulu workshop he is based in is fully functioning, '*but with services only for a target group of war victims*'.

A technologist working in Mulago similarly describes how some 'humanitarian organisations' required them to target refugees: '*They would bring their clients here and we made limbs for them, or we would go to the [refugee] camps*' (D10).

This raises another common problem with outreach work—namely the time and resources involved in travelling to reach patients. Where activities require transport funding (and usually per diems for staff) they typically come to a halt on the day the project funding ends. In other cases, public health workers are required to implement a donor-designed means-test:

> Not every patient is eligible to be funded. So, they [funders] have their own means testing scheme. Are you really from a poor family? They have their own tool that they use to assess. (D04)

Means-testing is a feature of many health systems. It is a blunt tool known to exclude many of those in need and support many who are not. The

[4] The Disability Symposium on Inclusive Health and Rehabilitation held in Kampala on December 5, 2024.

specific problem here is having foreign organisations implement a plethora of diverse means-testing tools that may be imposed on local partners and found hard to understand by health workers and the wider public. In the specific context of health care, it is hard to see how this sits alongside the principles of Universal Health Care and national commitments to free public services. It could also whip up discontent in a country that accepts so many refugees.[5]

Another form of 'discrimination' or prioritisation concerns limb type. It is rare to see donors involved in orthotic devices, for example, with most donors supporting either upper or lower limb devices. In most cases this implies a focus on lower limbs despite the fact that over 39% cases identified in a recent and expansive survey had lost upper limbs (Huck et al., 2022). The outreach camps discussed above all focused only on lower limb cases. This is also the case for a service funded at a PNFP Hospital supporting only Jaipur lower limbs:

> The funders don't provide any upper limbs, so we refer them. (T6)

One of the ICRC projects in Fort Portal, in contrast, only funded upper limb and provided a metal 'hook' for patients seeking a functional hand: '*With ICRC, we were mainly making cosmetic hands. We would give hooks for more functionality, but patients did not like them*' (T4).

We can anticipate a high rate of abandonment in such cases with few clients favouring the 'hook' device, but this is rarely captured in outcome measures (Ramirez et al., 2024).

[5] In November 2021 the UN estimated that Uganda is the country hosting the most refugees in sub-Saharan Africa with over 1.5 million refugees and asylum-seekers mainly from South Sudan, the Democratic Republic of Congo (DRC) and Burundi: https://www.unhcr.org/countries/uganda. It is interesting to note that a parallel area of work on the impact of open fire cooking on human health and the environment in Uganda found that international NGOs were providing 'clean' cooking stoves but only to refugees.

Patient Experiences of Accessing Prosthetic Services Through Private and PNFP Hospitals

Health 'tourism' is an increasingly common resort amongst the (growing) wealthier sections of Ugandan society keen to access what are perceived as the best quality products and services. India or Cuba are popular destinations to access private health care as are the many diasporic networks. Kwesigabo et al. (2012) list 'Referral Abroad' at the apex of their health systems hierarchy in Tanzania. Harkins et al. note that in many LMICs patients are sent to Europe or America for treatment (2012: 357). More commonly in the Ugandan context accessing high-end private health care will involve referral to Kenya or Tanzania for treatment.[6] These forms of health tourism fail to stimulate demand for materials in-country. They also fail to deal effectively with maintenance, repair and replacement of devices. Sekyonda et al. (2018) describe the 'Physician Mediated Procurement Pathway' operating in private hospitals. Here surgeons negotiate the price of orthopaedic implants at the bedside, and pass these directly onto private patients as a component of the overall cost. Although there are many private hospitals providing state of the art services in Kampala, there are no private (for-profit) rehabilitation hospital delivering comprehensive physical rehabilitation services. Instead, there is a myriad of small private workshops located across the country and nourished by informal networks.

Derrick's case illustrates how costs can explode and the opacity that exists around them. Derrick had paid a private doctor to amputate his leg (in a public facility). The same doctor referred him to a colleague who had a private clinic in Kawempe suggesting a cost of *1.8mUGS (£385)*:

> When I got there and was measured, he asked for an immediate payment of 200,000UGS (£43) for 'buying things'. I asked again how much are the costs for all the procedure and he told me he will give me feedback in three days after calculation. He called me back and told me 4mUGS (£855) is the final total. I asked him, 'but you had said 1.8m (£385) in the first place, why is he changing?' He told me the procedure was expensive. I asked him to give me time as l look for that money' but I did not return. (36)

[6] One of the most active companies in this field is Africa Air Rescue. AAR runs health insurance schemes: https://aar-healthcare.com/ug/aar-fee-for-service/.

We noted the peripatetic behaviours of some of Uganda's doctors and the practice of charging patients for surgery in public facilities. In this case the doctor was also using his personal networks to provide prosthetic devices outside of public workshops. The uncertainty about costs and fears of constant escalation is a major factor discouraging amputees from trying to access rehabilitation.

Whilst private hospitals do not currently provide physical rehabilitation services themselves, when patients access such facilities clinicians will use their private networks to contact orthopaedic technologists (usually those employed in the public workshops) who will operate peripatetically and arrange to meet patients in the private facility. This immediately illustrates the 'fuzziness' of the mixed economy in rehabilitation services; even the private sector is drawing directly (but informally) on public resource. Rather than requiring the private patient to access public workshops, casting and other procedures will be performed in the private fracture clinics. The orthopaedic technologist will then make the device, either in a public workshop or their private workshop, and arrange to fit it in the private hospital. It is not at all unusual for the technologist to use (and sell) second-hand componentry, donated by donors for those in need, in this process. The patient will then be billed by the hospital who will pass on a fee to the technologist for the product (and his/her time).

In other cases, and where patients are aware of their existence,[7] they may access private orthopaedic workshops directly. Many of these are owned by the same orthopaedic technologists employed in the public sector. These small clinics are also often registered as Community Business Organisations (CBOs) for tax purposes.

A significant 'Private Not-For-Profit' (PNFP) sector running in parallel with the public sector makes a major contribution to service delivery in the Ugandan mixed economy of healthcare (Approach 4 above). Many foreign organisations prefer to set up their own parallel services than attempt to engage with what they see as an entirely dysfunctional public sector that is resistant to change. Engaging in the development and delivery of such services is a prime example of the 'helper/comfort' motivation referred to above.

Not-for-Profit status does not mean that services are necessarily free or that profits are not made and distributed. In some cases, organisations

[7] Such services are rarely advertised so word of mouth and access to patients through public hospitals is the main recruitment method (see Chapter 6).

(such as Katalemwa[8] or CORSU[9] for example) are large UK-supported NGOs focused on providing services for children with disabilities. One advantage of this approach is the longevity and predictability of services and the much greater role of Ugandans in facility management and service delivery. CORSU (Comprehensive Rehabilitation Services for People with Disability in Uganda) was established in 2009[10] by a British doctor. Eighty per cent of its beneficiaries are children with physical impairments. Fees may be waived for specific needs or where individual sponsorship is available, and costs are subsidised by both the donation, in-kind, of goods and the raising of charitable funds overseas. In the case of CORSU, free services for qualifying children are in part subsidised by charging adults. In another example, the Katalemwa Cheshire Home[11] in Kampala, founded in 1970 by the UK-based Leonard Cheshire Foundation, provides high quality rehabilitation services for children with disabilities. Katalemwa also supports an integrated outreach model using a continuous Hub-and Spoke system:

> We have satellite organizations, NGOs and CBOs that do assessments and send specification orders for clients. We monitor and evaluate the work that these satellite organizations do and train them to do some maintenance on the devices. (T7)

This is a very different approach to outreach which is much more integrated and sustainable complementing in-patient services. A number of respondents reported attending or being advised to attend Kilembe Mines Hospital.[12] This hospital is located on the Western border with DRC in Kasese District. It was established in 1951 on a Private-not-for Profit (PNFP) basis initially serving the healthcare needs of Kilembe Mines employees. It later partnered with the Ministry of Health and currently serves the broader community of Kasese and neighbouring districts including Democratic Republic Congo (DRC) migrants and refugee settlements. Prosthetic services at the hospital are entirely donor

[8] https://www.katalemwacheshirehome.org/.

[9] https://corsuhospital.org/.

[10] About Us—CoRSU (https://corsuhospital.org/about-us/).

[11] Home | Katalemwa Cheshire Home (https://www.katalemwacheshirehome.org/).

[12] https://en.wikipedia.org/wiki/kilembe_mines_hospital.

funded by international NGOs such as the Rotary Club with payments required to make some contribution to access these services.

These Not-for-Profit organisations access materials in a variety of ways. In some cases, specific relationships have been established with foreign organisations supplying comprehensive 'kits' including all the materials required to assemble a device. Kagando Hospital, for example, has its own workshop funded by an international collaboration between the Rotary and Jaipur (a supplier of prosthetic limbs in India).[13] In this case the hospital charges patients to cover its own costs of service delivery and does not support (permit) the purchase of alternative limbs or materials. It is effectively a spoke on a monopoly Jaipur Hub based in Kampala. As such no purchases of materials are made in-country and no choice (of technologies or materials) is available to the orthopaedic technologists or patients.

CORSU, Katalemwa and other specialist NGOs source materials from 2 Kampala-based distributors. Where organisations are larger and demand is higher, they may also try to access international suppliers directly. Whilst these organisations have greater purchasing power, they still tend to buy relatively low volumes and hold limited stock. The ability to plan is often limited as sponsorship is unpredictable and often comes in the form of very specific requests (funding for 10 lower limbs for children for example with prescriptive outcome measures). It was clear from the interviews that these organisations and suppliers are struggling to manage procurement processes.

Our interviews would not have captured users who had successfully accessed PNFP facilities and been in a position to afford the associated costs. Table 4.1 shows the costs, as reported by respondents (cases 19, 45, 53 and 57). All of the cases cited involve people who made the decision not to access services on the grounds of affordability. Peter, for example, was advised by the surgeon who did his amputation to access a prosthetic device at CORSU:

> I had to look for money (for the 300km journey). They told me to wait a bit longer for the wound to heal and it [the device] would cost 4.5m. But I failed to get that money. (53)

[13] https://rotary-site.org/jaipur-limb.

Table 4.1 Costs quoted by respondents who considered accessing PNFP Facilities

Case	*Facility*	*Facility type*	*Cost in UGS*
19	Kilembe	PNFP	1,100,000
45	Kagando	PNFP	600,000
53	CORSU	PNFP	4,500,000
57	CORSU	PNFP	3,200,000

Even when the costs of accessing a limb are heavily subsidised, they may remain unaffordable. Meddie attempted to get a prosthetic limb in Kagando hospital (a PNFP facility near his home). Although the materials are provided by donors free of charge to the hospital the hospital proposed a charge of 600,000UGS (£128) and later reduced this to 150,000UGS (£32); '*it was still too much for me. I could not manage to get the money at that time*' (45).

The accuracy of these costs will depend on recall and reflect the date that they made the enquiry. They are also estimates and not the final bill, which is often much higher than that quoted. The prices range from 600,00UGS (£128) in one PNFP facility (where respondents advised us received free materials from the Rotary Club) to 4.5mUGS (£962) in CORSU, another PNFP but one that charges adults for services.

Conclusion

This chapter has described the experiences our respondents had of attempting to access physical rehabilitation services prior to intervention. It illustrates the fragility and systems-damaging impacts of poorly managed donorism. Dependency on donors for devices and materials has a profound impact on the roles and behaviours of Ugandan orthopaedic technologists under pressure and often remunerated to leave their stations and engage in inefficient and unsustainable outreach work. It also denies these workers the opportunity to make their own professional decisions about choices of technologies, equipment and materials leaving them in a situation of passive dependency and skewing their access to training according to donor priorities. The practice of avoiding local distributors and procuring devices and materials outside of the country (as 'in-kind' donations—particularly of whole limbs) also impacts supply chains and the potential for local manufacturing and economic development. Put simply, 'you get what you get given' and make do. The donation of

second-hand componentry has played a significant role in giving users access to high quality prosthetic devices in Uganda. It has also created important opportunities to recycle components that would otherwise go to waste in high income countries. Unfortunately, reliance on second hand components is often experienced as quite random and unpredictable and involving diverse and, at times, incompatible technologies. Moreover, in the absence of the provision of other materials for casting and socket manufacture these components cannot be used.

Whilst price predictability is greater in the PNFP sector the costs to adults are very high. Patients also expressed dissatisfaction with the quality of services particularly when delivery involved camps and outreaches. Concerns were expressed here about the quality of materials and componentry and the lack of time taken to fit and support their rehabilitation. In the longer term, support for adjustments and repairs leading to high levels of abandonment. 'Patient-picking' on the part of donors, often reflecting the specific priorities of funding bodies and donors distorts the behaviour of Ugandan health workers and disadvantages those who fail to meet often quite arbitrary and discriminatory eligibility criteria.

The system, as described, is not fit-for-purpose when it comes to Uganda meeting its commitments to Universal Health Coverage and 'Leaving No One Behind'. Achieving these commitments will require much greater mobilisation of the public sector. The following chapter outlines the delivery of prosthetic services in the Ugandan public sector.

CHAPTER 5

Leaving No One Behind? The Essential Role of the Public Sector in the Delivery of Universal Health Care

Abstract This chapter characterises the status of public rehabilitation services in Uganda and outlies the services they are currently able to offer and the impact of these on the ability to deliver Universal Health Coverage and 'leave No One Behind'. It identifies critical problems in human resource management and in access to materials and devices in poorly developed supply chains.

Keywords Human Resources · Leaving no one behind · Procurement · Prosthetic services · Supply chains · Universal health care

Introduction

Chapter 4 illustrated the continued reliance on donorism in Uganda and the unintended consequences of this in terms of developing comprehensive and effective rehabilitation services integrated in public health systems and capable of delivering Universal Health Coverage. This chapter examines the experiences of those amputee respondents who had not been able to access 'donor' services; those 'left behind' in the current 'system'. The United Nations defines its Leave No One behind (LNOB) principle as 'the central, transformative promise of the 2030 Agenda for Sustainable Development' arguing that, 'it represents the unequivocal commitment of

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all UN Member States to eradicate poverty in all its forms, end discrimination and exclusion, and reduce the inequalities and vulnerabilities that leave people behind and undermine the potential of individuals and of humanity as a whole' (UNSDG, 2022).

Formally, the Ugandan Ministry of Health continues to distinguish private and public facilities on the simple grounds of fee-paying:

'Whereas the private facilities charge a fee for services, public facilities provide services free of charge as they are publicly financed' (WHO, 2023c: 5). Bakwatanisa et al. (2016) remind us that, 'anything beyond basic services and supplies is dependent upon patients' ability to afford out-of-pocket expenses' (2016: 104). It was absolutely clear that the key driving factor prohibiting access to prosthetics among our sample was the need for Out-of-Pocket expenditure. The previous chapters have evidenced the catastrophic expenditures already incurred by most of our sample to save their lives and safely negotiate amputation. We can assume that many others will have died. At that point, respondents have already exhausted all personal and familial resources available to them and lost the ability to engage in productive work or subsistence farming. It is in that context that we now consider their subsequent health seeking behaviours and the financial barriers shaping access to public rehabilitation services.

Human Resources in Prosthetic and Orthotic Services

Chapter 1 noted the attention to the 'rehabilitation workforce' in the 2023 Strategic Plan. More specifically it referred to the 'underutilisation of rehabilitation professionals'. It is not uncommon nor perhaps surprising to see a lack of contextual specificity in many comparative global health reports which often gloss over national, sectoral or professional disparities. Certainly, when it comes to Human Resources for Health there is a strong tendency to over-emphasise medicine to the neglect of other disciplines. The recent Nursing Now campaign has recognised this and made serious attempts to raise the status and visibility of nursing as a profession.[1] The predominance of nurses as a proportion of the global health workforce underlines the importance of this campaign. Allied Health Professions are generally overlooked. Doctors

[1] Nursing Now Challenge (https://www.nursingnow.org/).

and nurses are universal professions with qualifications recognised across international borders. This is not the case for that group of health workers responsible for the provision of prosthetic and orthotic services. In the Ugandan context these services are provided by task-shifted cadres known as orthopaedic officers and orthopaedic technologists qualified to Certificate and Diploma level respectively. There are no separate training programs for prosthetists, orthotists or podiatrists and no degree level training in-country for orthopaedic technologists.[2] Furthermore, on the ground, orthopaedic technologists are expected to (and are able to) deliver multi-disciplinary services spanning prosthetics, orthotics, podiatry, physiotherapy and occupational therapy.

The 2023 Rehabilitation Strategic Plan notes that only 198 of over 1000 health professionals accredited by the Uganda Allied Health Professions Council in 2022 were employed in public service (p. 6). Recent analysis of the Health Labour Market in Uganda (WHO, 2023c) shows around 25 students graduating in orthopaedic technology annually (p. 33). This would seem a very low number. On the other hand, data also shows a 'stock' of orthopaedic officers at 890 and orthopaedic technologists at 392 (p. 37) suggesting that many qualified staff struggle to gain employment in public services.[3] This population also shows the youngest demographic profile of all health workers in Uganda with over 90% of them aged 34 or under (p. 41).

The Ministry of Health currently employs 36–40 orthopaedic technologists in 13 public workshops distributed across the country. The workshops are located in Referral Hospitals distributed across 15 Regions with a notional catchment area of 2 million people (2 Regions have no workshop)[4] (Fig. 5.1).

The human resource costs associated with funding over 30 orthopaedic technologists are not insubstantial but how do these technologists deliver

[2] Until recently Ugandan technologists travelled to TATCOT in Tanzania (Tanzania Training Centre for Orthopaedic Technologists) to do degrees but the degree program there has also closed.

[3] Those not employed in public services could either be working in the private rehabilitation sector or in other non-clinical roles; a neglected phenomenon often referred to as 'internal brain drain' or 'brain freeze' (Ackers & Gill, 2008).

[4] At the 2024 Census Uganda had a population of 45.9 million. 71.6% were below the age of 30, Uganda Bureau of Statistics, The National Population and Housing Census 2024—Main Report, Kampala, Uganda. https://www.ubos.org/wp-content/uploads/.

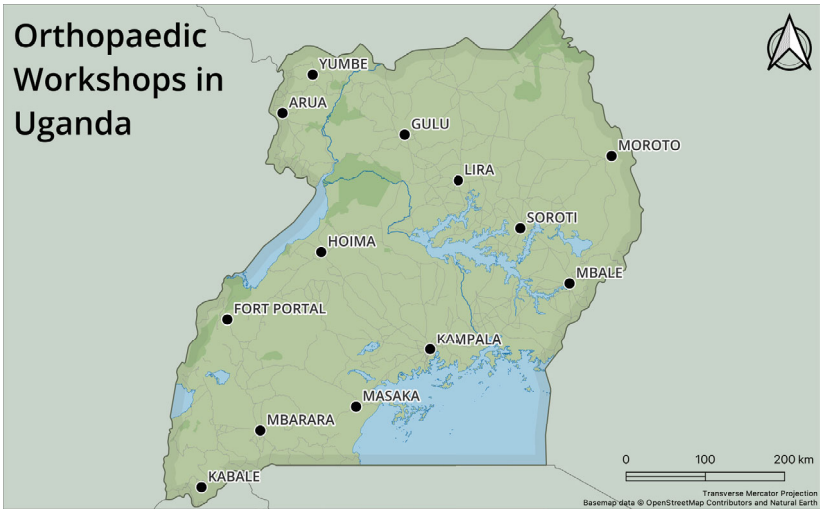

Fig. 5.1 Map of Uganda showing public orthopaedic workshops

services in the context of decaying infrastructure and the total absence of funding for equipment and materials? One technologist describes how this situation makes him feel:

> At the end of the day you feel you are not putting your skills to use, and you get bored. It is demoralising and people come in who we can't help and look at you as if you are useless.

Asked what the main obstacles were to service delivery, he is very clear: '*It's supplies. The facility is in place, most of the machines*[5] *are in good condition*'.

Q: What do you need most?

> Polypropylene, EVA, powder and bandages. (T04)

It is important to note that this respondent is referring to his own public workshop which has a relatively good infrastructure reflecting the care

[5] This legacy infrastructure was provided by humanitarian organisations that subsequently withdrew. It is rarely even maintained by the UMoH engineers.

he has taken to preserve legacy equipment. Other public workshops lack basic infrastructure. The overall state of equipment in public workshops is very poor. What equipment there is has been provided by donors often 20–30 years previously during times of humanitarian assistance. Donated equipment rarely comes with systems to maintain and repair. Although bio-medical engineering workshops do exist in Uganda it was clear that they paid little attention to the orthopaedic workshops. This may reflect overall priorities, the lack of visibility of the workshops, the specialised nature of some of the equipment or the lack of access to spare parts. The state of equipment in the National Referral Workshop in Uganda was by far the worst with little equipment working. The following respondent describes the impact of this situation on fabrication practices:

> Most of the ovens were not working and the compressor stopped. The only machine working now is this locally made oven. The suction machine that removes all the dust is broken down and the vertical sander. We have presented it all to the engineers at the hospital, they did some assessment and then say – we will get back to you. Because the heaters have broken down, we now use wet casts as we can't use plastics or laminate. So, the quality of the machines impacts the type of method we can use. I no longer mould any plastic – we have no PVC bags – we either don't have any funds to buy them or don't have the machines – lamination is better, but we can't do it. The International Community of the Red Cross bought us an oven and that team of Indians were using it, but the switch doesn't work, and we have no technicians to work on it for us. When we switch it on the power doesn't flow. (T01)

Urva et al. (2023) make similar reference to the lack of access to materials for prosthetic manufacture in public facilities in Tanzania. This chapter describes the level and nature of services currently provided in public orthopaedic workshops and the procurement processes involved. In order to understand procurement systems and the costs involved we have taken the technology most commonly used in public workshops and summarised the processes involved in the manufacture of a prosthetic limb. We then describe how the costs are calculated and passed on to those users able to co-fund ('cost-share') this process. Most of our respondents reported being unable to cover these costs. They also reported a variety of 'quotes' for devices reflecting the lack of any clear costing structure and the possibility that forms of cost 'inflation' enter this process. By exposing the costs involved in prosthetic manufacture the chapter seeks

to identify opportunities for cost-reduction whilst maintaining quality and professional autonomy. Our objectives are twofold. In the short to medium term, we hope to reduce the catastrophic out of pocket expenses to extend affordability to users within the current (unfunded) system. In the longer term, and in the context of momentum building around the emerging Strategic Plan on Rehabilitation we hope to build a credible evidence base to support advocacy for resource reallocation in favour of rehabilitation services.

Gavette et al. (2024) make a similar point albeit with specific reference to prosthetic services in an insurance-based system in the United States where, 'insurance companies call for greater evidence to document the clinical benefit of prosthetic technology … high quality evidence is crucial to justify the need and subsequent reimbursement of prosthetic technology (p. 4). Woods et al. (2016) underline the importance of detailed cost-effectiveness analysis, particularly in contexts where choices about novel interventions (such as rehabilitation services) have an 'opportunity cost' in terms of the health foregone because other interventions cannot be provided. Ultimately where resources are constrained (as is almost always the case in health systems) there must be a trade-off between different services. Leech et al. (2018) similarly point to the importance of cost-effectiveness analysis in terms of deciding what goods and services a system is willing to forego to achieve the potential gains associated with new interventions. Werner et al. (2021) make a critical point about costing (Emergency Care) services in Uganda that applies to all health systems and services but has a specific resonance in low resource contexts where critical decisions have to be made about resource (re) allocation:

'It is problematic to pledge resources to strengthen Emergency Care (EC) delivery systems without first understanding the cost. For this reason, knowing the true outlay of EC is essential to understanding the affordability or sustainability of scaling up services given already strained health care budgets in many LMICs. Hospital managers and decision makers require this information to engage in evidence-based decision making while setting priorities and improving efficiencies' (2021: 2).

McIntyre et al. address the concept of access to health services in LMICs from an economics perspective arguing that it needs more precise definition and more attention to its application and measurement. It is interesting to note the attention they give to the types of use, 'or perhaps more importantly, non-use of services in terms of how (and whether) the health care system interacts with individuals, households and communities (2009: 180). They link this to the issue of resource commitment:

> The economic problem of scarce resources means that no health care system can provide sufficient services to meet all needs for care. Hence, even in the most financially prosperous societies, choices much be made. (p. 181)

The Global Partnerships for Assistive Technology report on access to affordable, quality, prosthetic components (2021) suggests that the lack of government investment in rehabilitation reflects 'the lack of data and awareness of prosthetic need and economic benefits' (2021: 4). We would argue that understanding the costs involved in delivering services and, or specifically, in procuring devices and materials is of equal importance. Basic laws of supply and demand dictate that, where demand is poor and unpredictable, the costs of products will be high. Low volume sales undermine supply chain development increasing unit costs and limiting procurement options. The lack of government funding and punitive tax regimes combined with endemic corruption contribute to poor demand, but so too does the transport of in-kind donations. Our concern, in this chapter, is to raise the profile of supply chains in discussions about public rehabilitation services and focus attention on the need to expose and reduce the costs of materials used in prosthetic manufacture. Building effective supply chains is important not only to this process but also to improving the efficacy and reduce the externality effects of Overseas Development Assistance. In the longer term, supply chain development is necessary to create opportunities for health service interventions to stimulate manufacturing and wider economic growth; health markets in many countries are a major source of economic development.

Service Profile of a Ugandan Public Workshop

A previous paper (Mulindwa et al., 2023) describes the overall state of prosthetic services in Ugandan Referral Hospitals. The evolution of free public services in FPRRH has taken place over time as audit and accountability systems have developed alongside the Public–Private-Partnership funding mechanism. As such it is difficult to pinpoint a clear 'before-and-after' outcome measure. However, a snapshot of how the workshop was functioning in the period immediately prior to K4Cs engagement provides an indication of the kinds of activities this and other unfunded public workshops engage in in Uganda. Table 5.1 shows the data recorded by the workshop for patients attending for services over a 10 month period.[6]

Table 5.1 shows, that of the total of 142 patients recorded in the admissions book, the overwhelming majority (73%) attended for orthotic

Table 5.1 Patients attending FPRRH workshop (between Jan 1st and October 31st 2021)

Service type	*No*
Prosthetics	
Below knee	2
Above knee	3
Ortho prosthesis[7]	2
Repairs	18
Referred due to lack of materials	4
Review	1
	30
Orthotics	
Orthotic device (predominantly children)	44
Repair	23
Referred due to lack of materials	27
Referred for physiotherapy	4
Review	6
	104
Inadequate data	6
Walking aid (Crutches?)	2
Total	**142**

[6] There was a partial COVID-19 lockdown of 42 days from 7 June 2021 which limited movement between districts.

[7] An ortho prosthesis is used to manage a leg length discrepancy.

services. Forty-four patients, mainly children, were fitted with orthotic devices. These typically require significantly less material in comparison to prosthetics placing less of a cost burden on families. A further 23 cases involved repairs to orthotic devices with 27 referrals due to lack of access to materials. A total of 30 prosthetic cases were recorded with 7 of these receiving a device (which they would have funded from out of pocket expenses). Eighteen cases were repairs, often to very old devices. In 4 cases the records noted lack of provision due to materials shortages. In many other cases patients would not have even approached the workshop if they felt they lacked the resources to pay for their devices.

Understanding Device Manufacture in Prosthetics

The publication of the 'Priority Assistive Products List' by the World Health Organisation's Global Cooperation on Assistive Technology (GATE) program has played a critical role in advocating for the extension of Universal Health Coverage to the needs of people with disabilities (WHO/UNICEF, 2022). The List is designed to encourage governments to identify and fund Assistive Devices.[8] It also explicitly refers to procurement processes. Whilst 'lower limb prostheses' are listed (alongside wheelchairs, spectacles, and hearing aids) there is an inference that these are discrete devices rather than a composite of various materials and components that can be (best) fabricated, fitted, adjusted and repaired by qualified local orthopaedic technologists in situ.

Before discussing how patients access services in Uganda it may be useful, to a non-specialist, to describe the processes of prosthetic limb fabrication currently used by orthopaedic technologists in Uganda. To illustrate supply chain dynamics, we use a lower limb example here.[9] Many of the problems experienced by respondents in outreach camps which

[8] The WHO define 'Assistive Technology' as, 'products that maintain or improve an individual's functioning and independence', https://www.who.int/news-room/fact-sheets/detail/assistive-technology

[9] Technological innovation in upper limb co-design forms the focus of our EPSRC and MRC projects and is reported on elsewhere (Pickard et al., 2023).

contribute to device abandonment (and an absolute waste of resource) concern the process of socket manufacture. The socket fits over the residual 'stump' and must be both strong but also comfortable to the user. This is especially important in the case of diabetic patients where any friction could cause wounds. In all cases (at the present time at least[10]) Plaster of Paris bandages are used to take a cast of the residual limb. The cast is then filled with Plaster of Paris to form a replica (mould) of the patient's limb. A hard plastic 'socket' is then manufactured. There are 3 techniques used to manufacture this external 'socket'. 'Draping' uses a piece of polypropylene (procured in 2 m × 1 m sheets) that is warmed in an oven and wrapped around the cast and joined by a seam. 'Bubble Draping' uses a smaller sheet of polypropylene (procured in 343 mm × 343 mm for Below Knee,406 mm × 406 mm for Above Knee) that is warmed until it drops into a bubble that is then passed over the cast.[11] Finally, a technique known as lamination uses a liquid/paste that sets into the socket (procured in tins as a flammable liquid).

Once formed using one of the methods outlined, the hard plastic 'shell' is padded with a variety of softer foams.[12] Fabricating prosthetic devices that are acceptable to patients involves a combination of functional decisions (to deal with weight bearing, comfort and device longevity) with concerns about aesthetics. And the latter are shaped by culture and experiences of stigma in different contexts. In high income contexts users may have a different perspective perhaps preferring a high tech 'look'. The engagement of disabled athletes in the Paralympics has transformed attitudes. In the Ugandan context users continue to prefer prosthetic devices that mimic as far as possible the look of a human limb. In practice this means using a foot (rather than a blade) and covering the stainless-steel

[10] Innovations in 3D scanning may transform this process in future.

[11] Bubble-draping is often preferred because the smaller sheets are easier to transport. This method gives a socket that neatly conforms to the patient's contours with no seams improving the cosmetic appearance. However, this method requires vacuum equipment which has rarely been provided by previous donors.

[12] Creating a comfortable socket is a complex process and more than one attempt may be needed.

Fig. 5.2 Example of a prosthetic limb manufactured in Uganda (below knee or transtibial prosthesis)[13]

pylons with an outer coating of foams in a colour as close as possible to the user's skin (Fig. 5.2).

Table 5.2 summarises the process and the materials required at each stage.

The following section examines how procurement of the materials listed above takes place in unfunded public workshops.

Negotiating Procurement in an Un-funded Public Sector

Sekyonda et al. characterise the process of accessing orthopaedic implants in the Ugandan public healthcare system as the 'Hawker negotiated prescription model'. This model exposes the role of intermediaries in the procurement process when the Ministry of Health (through its procurement organisation National Medical Stores), 'does not seem to have the capacity and/or willingness to effectively and reliably procure' (2018: 5).

[13] A pictorial guide to this process can be found in Liao et al. (2020: 47) at: https://at2030.org/pn-prostheses/.

Table 5.2 Materials used in socket manufacture (below knee or 'transtibial' prosthesis)

Process	*Materials needed*
Step 1 Casting Plaster of Paris bandages are used to cast the patient's residual stump	Plaster of Paris Bandages (5–6)
Step 2 Mould The mould is filled with plaster of Paris powder to create an exact imprint of the stump	10 kg Plaster of Paris
Step 3 Soft insert A layer of preheated EVA (Ethyl Vinyl Acetate) sheet is wrapped over the mould to create a soft inner padding for comfort[14]	One 1 m × 0.5 m sheet of EVA foams and weighs (on average) 0.5 kg. 1 sheet makes 4–5 soft inserts
Step 4(a) Draping A sheet of polypropylene is heated and wrapped around the mould	One 2 m × 1 m sheet of polypropylene makes 8–10 sockets.[15] A typical sheet weighs 12 kg
4(b) Bubble Draping A square of polypropylene is heated to form a bubble over the mould	One 343 mm × 343 mm sheet is required per cast. A typical sheet weighs 1.3 kg
4(c) Lamination[16] Liquid resin is used to make a socket from the mould	Nylon stockinette, Cotton stockinette, carbon fibre, fibre glass, PVC, resin, hardener
Step 4 Assembly Two stainless steel adaptors are attached to both ends of a pylon (hollow aluminium cylindrical tube) of the desired length One end fixes the pylon to the socket and the other end to the foot	Stainless adaptors have 4 screws for controlling flexion, extension, adduction and abduction while providing attachment Aluminium pylon usually with an average of 40 cm Feet come in varying sizes, colours and types and depend on the user's needs

(continued)

[14] There is growing preference for silicone liners, but these are currently very expensive and only available in the private sector.

[15] Both types of polypropylene come in different thicknesses and this impacts both price and weight.

[16] This method is not currently used in FPRRH.

Table 5.2 (continued)

Process	*Materials needed*
Step 5 Trial Fitting To confirm fitting on patient	A proper stump sock is first worn over the stump Then the patient tries the socket Checkups are made on the socket fit and height
Step 6 External (Cosmetic) Facing Layers of Pelite are used to cover the pylon and trimmed to achieve a near close shape of a leg A final thin layer of EVA is applied for cosmetic finish	Pelite is a lightweight foam. One 1 m × 0.9 m sheet makes covering for 6–7 limbs (shall we focus on a below knee to be precise? EVA of 3 mm density is used and the brown (chocolate brown) is preferred for skin complexion one 1 m × 0.9 m sheet makes covering for 6–7 limbs (shall we focus on a below knee to be precise? Add weights?

According to this model (Fig. 5.3) the hospital itself 'plays no role in the purchase of implants by patients' with health workers (in this case surgeons) 'recommending a vendor to the patient who is then required to purchase and supply their own implants through external suppliers' (2018: 3).

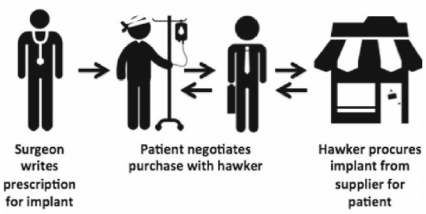

Fig. 5.3 The Hawker negotiated prescription model at public hospitals (*Source* Sekyonda et al. 2018: 4)

Prior to intervention, and faced with a patient requiring, for example, a prosthetic leg, technologists in FPRRH would assess the patient and see if they had any suitable donated (second-hand) components[17] available (joints, feet, pylons etc.). They would then do an estimate of the materials and components required to fabricate a prosthesis. In a similar way to that described in Sekyonda et al.'s paper, they would then inform the patient of the costs of materials and connect them to one of two distributors (in Kampala) who stock them. The process is described by a local researcher:

> If a patient can afford to pay for materials [the technologists] refer them to two main suppliers in Kampala and say, 'You buy this, this and this', then the team would make them something. It's obviously very discriminatory as only a few patients can afford it. The rest really get sent away. (R03)

The Government's insistence that services are free, coupled with strict anti-corruption measures (so technologists cannot handle cash) then requires the patient to pay the distributor directly, typically using mobile money transfer. Once purchased (and assuming the materials are in stock) they are transported efficiently via local buses, at patient's' cost, and arrive within 1 or 2 days. Figure 5.4 illustrates the calculation process for a below knee (transtibial) prosthesis:

What is immediately clear is that the technologist does not 'buy-in' an off-the shelf device as such. Rather s/he assembles the device using a range of consumables and componentry. STAND (formerly Legs4Africa)[18] is a UK-based charity that collects large quantities of second-hand componentry globally and distributes them to partners in LMICs. In the case illustrated in Fig. 5.4, a donated foot in the right size was not available so the price of that is added to the total.

In this process, items are typically purchased for a specific client and in very small quantities. A technologist explains:

[17] Most of these components are manufactured by Ottobok and are very expensive to buy new. One of the legacies of this form of donation is that it raises the expectation of technologists and patients (as seen in T19).

[18] Recycle Prosthetic Legs | Amputee Charity I STAND At the scoping stage of this project, we found boxes of STAND (and other donated) components in the main hospital stores; unused largely because technologists did not have access to the basic materials required to utilise them in device fabrication.

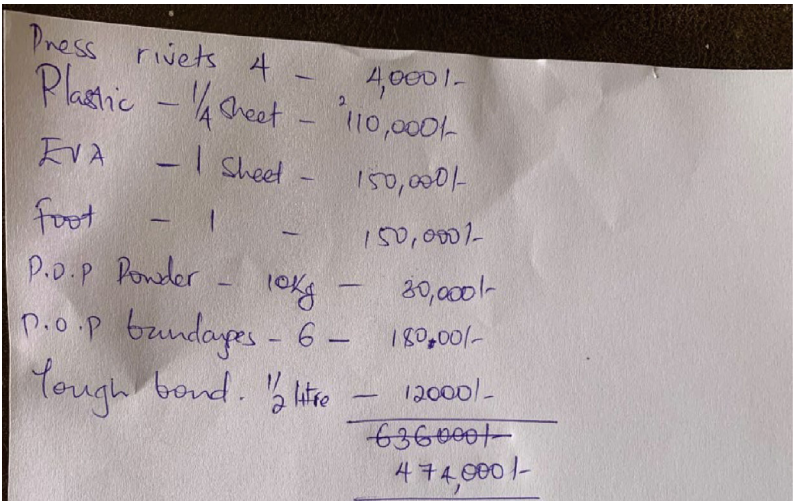

Fig. 5.4 Example of a calculation of costs for user-payment (below knee or 'transtibial' prosthesis)

We don't receive anything [from the government]. We have been trying to bargain [with the hospital] but we don't get. If someone comes, we check what we need and order from Kampala. There are some private people who import plastics and knee joints. It costs 400,000UGS for a 1m by 2m sheet [of polypropylene]
Q: Would you order 1 sheet if someone came in and had their own funds? You cannot order 1 sheet because you are not going to use the whole sheet for that 1 person. You order what you are going to use – maybe half a sheet for a prosthetic leg. A child may use a quarter sheet. We write down what is required; EVA, talcum powder, glue, POP, give the patient the phone number and they call the companies and pay. The patient is in charge of getting them. We don't want to [handle cash]. This has brought us problems. See behind you (pointing to a poster saying all hospital services are free and advising patients to report any charging to the hospital). It is somehow secure – if someone gives us the money and they don't get the things we could be arrested. Our hands are tied because it is a government facility, and they don't expect you to buy stock. The company will charge 10,000 per sheet for transport and put it on a bus and it takes 4-5 hours to come. (T04)

The prices quoted here are broadly in-line with some of the prices cited by respondents who had attempted to access services at FPRRH prior to intervention but found them unaffordable. Those patients who attempted to access services in other public workshops including the national workshop in Mulago and the workshop in Mbarara were much higher. This could indicate the need to buy higher value components (such as knee joints) but could also be evidence of other elements of cost—inflation (Table 5.3).

Much of the emphasis in existing research supports the 'common sense' assumption that distance from services (the 2nd delay) is the key barrier to access for these patients. This assumption underpins the approach to outreach models.

One health worker (but no users) mentioned this alongside the much more common concern about device cost:

Table 5.3 Costs quoted by respondents who considered accessing Public Facilities

Case	*Facility type*	*Device type*	*Cost in UGS*
56	Regional Referral Hospital (FPRRH)	Below knee[19]	500,000
15	FPRRH	Below knee	600,000
31	FPRRH	Below knee	400,000
35	RRH (Mbarara)	Below knee	2,500,000
37	National Referral Hospital (NRH)	Below elbow[20]	1.5–2,000,000
39	NRH	Below knee	2,000,000
47	NRH	Above Knee[21]	2,500,000
30	NRH	Below knee	1,100,000
11	NRH	Below knee	1,000,000
38	NRH	Above knee	1,500,000
13	NRH	Below elbow	3,000,000
20	Unknown	Above knee	2,000,000
03	Unknown	Below knee	800,000

Source Respondent Interviews. The accuracy of these figures cannot be verified and may have been quoted some years ago

[19] Technically a Transtibial device.

[20] Technically a Transradial device.

[21] Technically a Transfemoral device.

> Most patients cannot access services because they are too far. The cost [is also a factor]. A friend of mine got a prosthesis 10 years ago. It was very expensive for him at 1 million in Mulago. To hear that a prosthetic device is 1 million, that alone would make them remain at home. (HW1)

The experience of our respondents suggests that '3rd Delay' (service) costs constitute the main barrier. To some extent this reflects the fact that transport (and attendant) costs are predictable and can be planned for whereas service costs, especially in the public sector, are not. Hassan, for example, in common with most of the respondents visiting Mulago, travelled 300 km to find that he was unable to afford the device: '*On arrival I was told I had to pay 2.5 million. I did not have that money*' (47).

The reader may ask, why did Hassan and other respondents not ask about prices in advance—maybe search the internet or telephone the workshops? Certainly, the costs for individuals will vary according to their prescription and personal preferences. But the main reason here is that public facilities cannot or will not quote prices in this way—even estimates. This may reflect the fear of explicitly breaching the principle of free public services or the practice of assessing how much patients can afford: the 'visual means test' (Ackers et al., 2018).

When considering costs in the context of amputee's lives, we need to recognise household income holistically.[22] As noted above many Ugandans (and most of those living in rural areas) are engaged in 'small-scale' farming often for subsistence. When amputees have lost their previous employment growing their own food becomes even more important. Prisca describes how she weighed up the costs of obtaining a prosthetic leg from Mulago which she was told would cost her at least 1.5mUGS with concerns about its usability and her other financial commitments: '*I heard rumours that that leg is stiff and does not have joints and could not be useful. Besides, I could not afford to buy it. I only have chickens left. I sold the rest of my animals to raise money for my treatment in hospital and school fees for my children*' (38).

[22] The average income in Uganda is 80$ or £63/month (https://www.worlddata.info/africa/uganda/economy).

Most amputees will not be in productive employment and there is no social security system as such.

In another case, the respondent was told that a limb would cost 2 m UGS at Mulago. He was offered 500,000 by a local disabled person towards the costs but, '*decided to spend the money on a cow instead*' (39). While his decision may seem shocking to some, it is quite a pragmatic response balancing his disability with his reliance on subsistence farming for income generation.

The Impact of Procurement Systems in the Public Sector on Market Demand and Device Costs

The previous sections have demonstrated two consequences of reliance on out-of-pocket expenses in public services; namely the very patchy and sporadic nature of procurement and, secondly, the lack of affordability. This next section looks at the impact that this form of 'Just-in-Time' procurement has on in-country demand and supply chains. The method of buying supplies described above is the only option available to technologists in public facilities stuck between the lack of public funding and the principle that patients can't pay for services. However, it is a very expensive form of procurement:

> When you're buying small quantities, per individual patient, that's really expensive. Because you're not buying in bulk. (R03)

> Quite often [technologists] are buying small amounts randomly at different times. There's no consolidated demand which would enable an organization to buy in bulk and sell at a lower price. (R01)

When one of the K4C team explained the objective of predicting demand in the public workshop to an international supplier, the supplier expressed pessimism:

> They won't do that [plan ahead] because they buy as and when they need because a patient shows up and they cost the product for that patient. The patient will put a down payment, and the technician will source the components. This is the same in Kenya, so you'll never be able to consolidate materials orders from the workshops. (D05)

The lack of demand has a wider impact on the ability of the 2 existing distributors to warehouse materials and buy in bulk themselves and this

impacts supply. One respondent reported that local distributors, '*don't have a price list as they don't hold any stock; they just buy in materials and components once customers have made an order causing long lead times*' (R06).

Several respondents also noted the impact that weak demand has on the emergence of distributorships. A surgeon with his own private clinic in a more rural area describes the challenges of accessing orthopaedic supplies and the perceived lack of profit margin:

> I have my own pharmacy here. If there were cases [enough people buying] I would put the supplies near, and they would be able to get them with ease. It is a very slow-moving business. You can bring things in but they take years to be bought. The only advantage is that most of those things do not expire. It also needs a lot of money to start supplying orthopaedic appliances. (HW1)

An interview with a distributor in Tanzania suggested that the lack of suppliers and stock reflected both access to capital but also logistics involved in these processes:

> There is a lack of distributors in Tanzania due to the cumbersome logistics; it puts people off. I think I'm the only supplier. Why? Because getting the capital is not easy and most people fear going to authorities and asking for these permits and doing all this logistics. (D04)

It is interesting to note that both distributors in Kampala run their own clinics and are registered as not-for-profit organisations themselves. They also reported constant challenges with the bureaucracy and complex tax, customs and pre-inspection regimes for these products many of which fail to quality for tax exemption as 'medical supplies'.[23]

The discussion above has demonstrated the impact that the lack of public funding has on gaining access to affordable supplies for prosthetics manufacture. Public funding and mainstreamed procurement through National Medical Stores could improve access to supplies. It could also generate a 'market shaping' effect. The chapter has alluded to the role that supply chain development could have on wider economic development and manufacturing potential in LMICs.

[23] This issue is discussed in more depth in Chapter 6.

In resource-poor settings the public sector alone is unlikely to have the kick-start required for supply chain development. This is where the mixed economy approach could pay dividends especially if ODA is also harnessed in this process to create the demand and opportunities for 'pooled procurement' (Savage et al. 2021: 215) necessary for effective supply. At the present time the direct supply of materials by donors undermines this.

Whilst PNFP organisations have some potential to augment demand they also reported serious challenges in accessing supplies. One PNFP respondent noted the lack of supplies in-country:

> Accessing consumables (POP bandages, POP powder, Polypropene and EVA) is still a challenge because most are not readily available in the country. Majorly polypropylene in different sizes is not available and suppliers are not reliable in times of need. Suppliers rarely had EVA, so we resorted to using microcellular rubber which isn't the best but the only cheaper option. The only EVA we have had recently was a donation from China. (T11)

Another reported the impact that their funding mechanisms (described above and often linked to specific outcomes) has on procurement planning:

> We have reduced on stock. Before we could order 50 sheets. Now we order about 20 because of funds and these are the challenges as it's the same transport costs and everything.
> Q: So, if you reduce orders by half you pay more than half?
> Yes. (T07)

Access to some of the more bespoke componentry is even more complex and involves 'shopping around' through networks of contacts in Uganda and neighbouring countries:

> Limb components are not very available in Uganda. We have to look for them among colleagues but that is not as successful. (T07)

Purchasing in this way and on a tight budget can result in poor compatibility and outcomes:

> The technologist will contact colleagues in clinics throughout Uganda and neighbouring countries to see if they have the components required within their donated stock. If the components can be acquired the patient will be contacted and presented with the price of the limb before the components are ordered. These components are given based on whether the patient can afford the contribution. When componentry is acquired, it is often not compatible between the modular systems and requires mechanical adaptions and this can lead to mechanical breakdown. (R08)

Conclusions

This chapter has outlined the impact of zero public funding on procurement processes in public sector workshops in Uganda and the impact this has both on user access to services but also on the wider costs of prosthetics. It also demonstrates the impact of weak demand on supply chains and the potential for technology transfer, local manufacture, and economic development. Sekyonda et al. flag this issue in their work on orthopaedic implants arguing that local manufacture may be important in ensuring the long-term availability of components, contextualised to the needs of the local setting (2018: 6). The following chapter presents the intervention that has taken place in Fort Portal Regional Referral Hospital and the impact this has had on access to services.

CHAPTER 6

Promoting Free Public Prosthetic Services Through Social Enterprise: The Ninsiima Rehabilitation Centre

Abstract This chapter describes and evaluates an intervention in the Orthopaedic Workshop attached to Fort Portal Regional Referral Hospital (FPRRH) in Uganda. It opens with a short history of the workshop before describing the evolving intervention and the outcomes achieved. The intervention focused on the processes put in place to improve the procurement of materials for prosthetics manufacture and reduce the costs associated with these services. It also explains the role that social enterprise and Public–Private-Partnerships in Health have played in generating sustainable systems change.

Keywords Public–private-partnerships in health · Social enterprise · Supply chains · Prosthetics manufacture

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Introduction

This chapter describes and evaluates an intervention in the Orthopaedic Workshop attached to Fort Portal Regional Referral Hospital (FPRRH) known as the Ninsiima Rehabilitation Centre.[1] We open with a short history of the workshop describe the evolving intervention and the outcomes achieved.

The Orthopaedic Workshop at FPRRH

Fort Portal City is close to Uganda's border with the Democratic Republic of Congo (DRC) and hosts a number of well-established refugee communities.[2] The Workshop is typical of all 13 Regional Workshops in Uganda in terms of staffing and donor-dependency. In 1996 an Italian NGO[3] (AVSI) established the workshop infrastructure in Fort Portal to support people injured in the ADF (Allied Democratic Forces) war with Congo and associated refugee communities.[4] One of the orthopaedic technologists describes how services evolved in the 1990s:

> The donors just came. There was no negotiation. The deal was done with the hospital without our involvement. We saw that people had come to assist us so there was nothing like asking. We had to go out to assess

[1] 'Supporting the Delivery of Universal Health Coverage for people with Physical Disabilities in Uganda, Knowledge For Change Project Report (2022) https://knowledge4change.org/projects-research/rehabilitation-programme/.

[2] Kyangwali Refugee Settlement in Kikuube District was established in 1960 predominantly for DRC refugees, with some Rwandese and South Sudanese. Kyaka II Refugee Settlement was established in 1983, mainly with refugees from DRC, but also includes Rwandese and Burundians. Nakivale Refugee Settlement in Isingiro district was established in 1958, originally settled by Rwandese but now home to refugees from the DRC, Burundi, Somalia, and other countries. Rwamwanja Refugee Settlement in Kamwenge District was established 1964 and reopened in 2012 hosting refugees primarily from DRC: https://data.unhcr.org/en/country/uga.

[3] AVSI describes itself as a non-profit organization which carries out development cooperation and humanitarian aid projects throughout the world. It currently supports the Gulu orthopaedic workshop in Northern Uganda supporting the victims of the civil war in that region https://www.avsi.org/en/what-we-do/countries/uganda.

[4] https://www.aljazeera.com/news/2024/2/21/a-guide-to-the-decades-long-conflict-in-dr-congo#.

> patients mainly in the Kasese region.[5] Then the patients would come, and we worked on them. Handicap International (another NGO) was facilitating some patients. They would give them upkeep that is why the numbers would be high. Then, when they left the services go down. (T3)

The International Red Cross (ICRC) later began to support the workshop as part of its humanitarian support for refugee communities. At this time, and in another perverse 'twist' in the Aid story referred to in Chapter 4, prosthetic limbs were provided almost exclusively to refugees (who came with a budget) leaving equally disabled and poor Ugandan citizens unsupported. Anderson et al. (2017) in the rather different context of emergency surgery noted a similar form of discrimination against nationals most of whom faced catastrophic out of pocket expenses: 'It is ironic that the largest source of charity was the United Nations which covered all the cost for the care received by refugees from a local camp. Their care truly was free' (2017: 10). This is the kind of donor-approach critiqued by Harkins et al. as potentially fostering 'local resentment of foreign programmes' (2013: 358).

Huck et al. make a similar observation, with reference to the context in Northern Uganda distinguishing clients not so much by refugee status but on the cause of their limb loss: 'many NGOs currently provide support only to those who lost limbs as a result of the war; meaning that approximately half of the population of people with MLL have no access to rehabilitation services whatsoever' (2022: 379).

Between 2008 and 2011 the ICRC supplied materials and components to the FPRRH workshop as well as machinery and infrastructure. The materials and components were supplied directly from Geneva and reflected the manufacturing technologies prioritised by the ICRC approach (in this case draping technology) but with no consultation with technologists. When ICRC funding ended the materials were exhausted, and the workshop ceased to offer free services. Other components (hands and feet) disintegrated as a result of humid conditions and were not usable. In 2011, ICRC put pressure on National Medical Stores to supply the workshop. NMS subsequently made one delivery of materials and components. This was described by technologists as an attempt by NMS

[5] The Kasese region stretches from Kasese town about 45 miles from Fort Portal right down to the border with DRD. FPRRH is the closest public hospital but there are more proximate PNFP facilities.

to trial prosthetic material procurement which ended in failure due to the poor quality of materials. Once again, the technologists were not consulted about the choice of materials and componentry:

> The ICRC supplied materials from India. The materials had issues, and we said, 'when you are ordering why didn't you ask a technical person?' The plastic and tools were terrible. The sandpaper couldn't even be used. They purchased the lowest value items. That was 2011 – after that nothing. (T3)

Handicap International continued to provide funding enabling an influx of refugees crossing the border into Uganda to access services at the workshop. This funding supported individual refugees and covered their transport, subsistence and materials. The lack of concurrent government support deprioritised the treatment of Ugandan nationals creating longer waiting times and denying them access to materials. In practice, this also implies a skewing of what funding was in place in favour of non-nationals:

> However, the UN funding for Congolese refugees did not cover the whole cost of the rehabilitation process which was absorbed by the limited government and charity funding as well as patient 'donations' (Out-of-Pocket expenses). (R2)

The technologist leading the facility explains how this was not only unsustainable, it also raised expectations and confused communities who came to expect services to be free and, if a charge had to be made, suspect corruption:

> They work within that specific period and after that the contract ends - it is not sustainable. When they leave everything goes down because they were providing us with components, supplies and materials. So, the patients reduce and the visibility of our services within the hospital reduces. (T3)

It is interesting to see the respondent make the link between funding for materials and the status of the workshop within the hospital. This in part explains the 'peripheral' feel of the workshop.

The Intervention

The development of the Health Partnership linking FPRRH and Knowledge For Change and supported by researchers at the University of Salford was outlined in Chapter 1. This organisational partnership formed the essential platform, based on trust relationships, fostering our engagement in rehabilitation services and social enterprise (Magoola et al., 2023). At the start of this process the Workshop was functioning in the way described in Chapter 5. Only 3[6] of the 6 positions designated for orthopaedic technologists at the hospital were filled and the workshop received no support with infrastructure, equipment or procurement. When the above funding streams targeting refugees were withdrawn, the workshop was largely doing patient reviews and repairs. An initial assessment visit found that the workshop was very well managed with most aged equipment working but in need of servicing. It is interesting to note that the hospital biomedical engineering workshops are generally reluctant to maintain and repair equipment in orthopaedic workshops. It is almost as if orthopaedic technology is not viewed as an integral part of hospital services.[7] This also reflects the historical legacy of overwhelming donor dependency and the lack of engagement of public sector engineers and managers in equipment procurement processes (Oshabaheebwa et al., 2020).

The peripheral feel of the workshop is further evidenced by the lack of support from the Hospital Procurement Plan. This reflects the lack of priority attached to rehabilitation in a hospital overwhelmed with emergency medicine and/or its historic dependency on 'external partners' (ODA). Even where materials are on the procurement plan (such as Plaster of Paris bandages for example) the staff have to 'bargain' with the hospital stores. They rarely receive even these simple consumables as priority is given to outpatient fracture clinics.

During his time in the UK, supported by a Commonwealth Professional Fellowship, the lead technologist established links with STAND[8] a UK-based charity that collects and donates second hand prosthetic

[6] This later dropped to 2 when one was removed for theft of K4C materials.

[7] This 'disconnection' is also reported in the UK NHS Orthotic Report Final Version_0.pdf (https://www.hee.nhs.uk/sites/default/files/documents/Orthotic%20Report%20%20Final%20Version_0.pdf).

[8] https://stand.ngo/2024/05/30/we-are-stand/.

components. This led to the donation of a small volume of components which reduced the cost of devices for some service users. Further consignments were later sent via the National Referral Hospital workshop. What was sent at that point was described as, 'unpredictable and random and took a long time [to arrive]'. Our initial visit found that even this small volume of donated components was stored in the main hospital store and not the workshop. This decision reflected concerns by the existing staff about accountability and risk of theft by other technologists.

Chapter 4 noted the tendency of donors to supply whole limbs and some of the limitations of this approach in terms of user abandonment and repairs. Supplying whole limbs is perhaps just an easy option avoiding the need to really engage with manufacturing processes and the supply chains associated with them. In order to respond to the legitimate questions Ugandan technologists raised about their involvement in decisions about technologies and materials our intervention first sought to understand the manufacturing process and materials required from their perspective.

Improving Procurement Processes: (i) Identifying Optimal Materials and Componentry

As noted in Chapter 5, the constituent materials used in the fabrication of a prosthetic leg[9] can be grouped into three categories:

1. **High Value 'Bespoke' Componentry**
   The most expensive or 'bespoke' items such as knee and ankle joints, connecting pylons, and feet are often sourced through donations of second-hand components from high income countries. These are typically manufactured by 'high-end' suppliers such as Ottobock.[10] Where donated components are not available, and if the patient can afford it, specific orders can be placed for less costly components from suppliers in India and China. The latter are often experienced as inferior in quality by technologists and users. This perception of the quality of Chinese and Indian products reflects the specific experience of Ugandan technologists, and Ugandan society in general,

[9] We are using a lower limb example here as this forms the majority of cases.

[10] https://www.ottobock.com/.

exposed to very low-cost imports and lacking exposure to the latest technologies and higher value materials produced in these countries.

2. **Imported Generic Materials**
   The 'bespoke' components are assembled into a prosthetic device using a range of more 'generic' materials including the hard plastics (polypropylenes) used to make the 'socket' that fits over the residual limb and the softer foams to provide internal padding and external cosmetic finish.
3. **Locally Available 'Ubiquitous' Materials**
   Finally, technologists require a range of 'ubiquitous' products to complete fabrication. This includes large volumes of Plaster of Paris bandaging and powder for casting, and various glues, rivets and strappings. These items are more generally available from Kampala and delivered by bus at one day's notice. Except for bandages (provided mainly to outpatient clinics) none of these items feature on the Hospital Procurement Plans that trigger quarterly supplies from National Medical Stores (the UMoH's monopoly supplier).

We have referred to the important work of ATScale in raising awareness of the global need for Assistive Devices. Their 'market landscaping report' (2021) makes an important step away from the generic presumption that devices are always discrete commodities acknowledging the importance of specific components such as feet or knee joints (p. 8). Unfortunately, they do not provide parallel analysis of markets supplying these essential materials. In recognition of the rather different supply chain dynamics and the objective of optimising the potential for a 'market shaping' intervention, at this stage in our intervention we took the decision to deal with these groups of materials separately.

1. To access the necessary 'Bespoke components' we signed an MOU with STAND and engaged the technologist team in the procurement planning process (and related accountability systems) so that supply is more closely aligned to current, and projected demand.
2. In terms of the 'Ubiquitous' items we have sourced and compared products available on demand in local markets. In some cases, we have found that materials carrying a reputable label such as 'Tough

Bond' glue are poor quality imitations[11] (a process known colloquially in Uganda as being 'baptised'). This has led us to change suppliers.

3. Our primary focus at the present time has been on the 'generic' plastics and foams that require international importation but are used in all prosthetic and orthotic[12] devices.

Supply Chains in Thermoplastics and Foams

The generic plastics and foams are currently imported from a range of higher and lower cost international suppliers. There is very limited supply of these materials in Uganda with only 2 small, specialist distributors based in Kampala both of which run their own private clinics and hold limited stocks. Perhaps because of lack of exposure to international suppliers or the convenience of dealing with only one company, a very narrow range of densities, sizes, colours (and prices) are available. Ottobock are typically perceived by technologists to offer the 'gold standard'. This perception may be skewed (as Sekyonda et al. suggest) by 'implementing partners' who have donated products to passive recipients restricting wider product exposure. Our findings echo those expressed in the ATScale Global Partnership for Assistive Technology Report (2020) which refer to the global dominance of a few large companies (taking 75% share of the market in value) leaving 'many buyers unaware of the smaller companies' (2020: 4). The market dominance of Ottobock combined with disappointing experiences of one or two donated alternatives has limited exposure of in-country distributors and local technologists to alternative products.

Chapter 5 described how current funding mechanisms result in sporadic and very low volume procurement. This contributes to the lack of purchasing power that Danemayer et al. (2021) refer to that fails to stimulate the emergence of local distributors and associated supply chains.

[11] In breach of copyright.

[12] To maintain some simplicity, we have not discussed the process of orthotic fabrication. Orthotics use the same range of generic plastics, often in large quantities, to manage damage to limbs, backs and necks. They are commonly used to treat growth deformities in children including club foot, genu varus (knock knees) and geno varum (bowlegs).

Current practices could be characterised as one form of 'Just-in-Time' procurement described as a production strategy, 'that aims to produce goods or services exactly when they are needed, and in the quantities demanded by customers. Celebrated in the international business literature as a way to 'minimize waste, reduce inventory levels, and increase efficiency in production processes' the strategy requires producers to be able to accurately forecast demand.[13] At the present time, uncertain demand coupled with lack of adequate forecasting also implies reliance on air freight which takes days rather than the 3 months required for shipping. Further delays and additional costs are incurred in the process with a series of 'middlemen' (clearing agents, distributors etc.) hiking prices and orders incurring pre-inspection charges and customs taxes. This all combines to inflate the costs of prosthetic devices.

The following sections deal with each of the issues raised above, in turn. We start with a discussion about how to create demand (sales) in an unfunded public system. Then turn to how to get unit prices down to optimise sales and affordability. Increasing sales volume is a key way of reducing unit costs but achieving this requires improved forecasting and this, in turn, needs much improved audit mechanisms. And that, rests on a transformation in behaviour, trust and organisational cultures so damaged by corruption, anti-corruption measures and donorism.

Creating Demand through Social Enterprise in the Public Sector?

Recognising the demand that already exists in the private sectors and could be further stimulated and harnessed is important. The lack of coordination, compounded by the fact that much of this enterprise takes place behind a smokescreen in the 'informal economy', prevents consolidation of this demand to support the development of effective and affordable supply chains. Whilst recognition of this intersectionality is crucial in the longer term, our project focused in the first instance on how to deliver free prosthetic services in cases where limb loss threatens catastrophic out-of-pocket expenditure. Put another way, how do we stimulate demand in an un-funded public sector and build an evidence-based case for statutory

[13] https://www.planettogether.com/blog/advantages-and-disadvantages-of-just-in-time-jit-manufacturing.

funding for Universal Health Coverage? This question breaks down into 4 sub-questions:

1. How can we identify and stimulate income streams to nourish the public sector and create demand whilst avoiding the damaging impacts of Aid-dependency?
2. Which specific products are needed in prosthetic (and orthotic) fabrication?
3. What specific costs are involved in getting these products to public workshops?
4. What potential is there to reduce the costs of these products (and services)?

Stimulating Purchasing Power in the Public Sector

The first intervention cycle focused on identifying and trialling a new approach to Public–Private-Partnership (PPP). Joudyian et al. (2021) define public private partnerships as 'voluntary cooperative arrangements between two and more public and private sectors in which all participants agree to work together to achieve a common purpose or undertake a specific task and to share risks and responsibilities, resources and benefits' (2021: 2). Their scoping review describes PPPs as flexible in nature as they respond to local needs which 'could include the establishment of a sustainable financial system [..] or increasing demand for health services'. And, notably, they argue that PPPs can be particularly valuable when the market fails to distribute health benefits to those who need them (p. 2). They also identify a number of challenges especially at start-up and implementation stages. These include limited strategic vision, concerns about the long term sustainability of financial mechanisms and associated monitoring and documentation systems—all exacerbated where there is a lack of trust (points we return to below).

The Ugandan government passed a National Public Private Partnership Policy in Health (PPP/H) in March 2010 (Ministry of Finance and Economic Planning, 2011). The UMoH then established an Advisory Committee to draft Uganda's PPP/H Strategic Plan published in 2017 (Uganda Ministry of Health, 2017). The basic premise was that leveraging cooperation between the public and private sectors would be

mutually beneficial. The key objective was to harness fragmented private initiatives to 'overcome systematic deficiencies in the public health system and the inability to meet the growing demand for quality health care' as well as improving access and preventing 'impoverishment'. The Strategic Plan recognised the contribution that an inter-sectoral approach could make to improving innovation, efficiency and cost-effectiveness (p. 11) and makes specific reference to the existence of 'parallel supply chains' driving inefficiency (p. 27). The situational analysis notes that Private Not For Profit (PNFP) providers operate around 30% of health facilities (p. 15)[14] and outlines various PPP/H Models advocating the use of Memorandum of Understanding (MOUs) to facilitate collaborations between public and private sector organisations.

Whilst the concept of PPP/H is very broad in scope, in practice its current interpretation in Uganda fails to challenge the 'donor' model. In many ways the hybridity of existing systems blurring public and private services, and sustained through endemic corruption, could be described as highly functional (informal) forms of PPP/H, so the concept is not entirely novel. The key question is the form that the PPP/H takes. Knowledge for Change (K4C) is committed to supporting public services rather than creating parallel institutions or directly engaging in service provision. K4C is fundamentally opposed to the principle and culture of 'donation', having witnessed the impacts of this on partnerships and the dependency, passivity and opportunities for corruption it encourages (Ackers-Johnson & Ackers, 2016). It is with this in mind that we sought to co-develop a sustainable social enterprise innovation to enable a public hospital to deliver Uganda's commitment to free orthopaedic services.

K4C manages a highly successful Ethical Electives Program (Ahmed et al., 2017),[15] founded on Fair Trade Principles, with undergraduate students from UK, Swiss and Norwegian Universities undertaking placements in public health facilities. K4C sets aside a sum of £150 for every student placement to support local investment. The placement of students from high income settings in LMIC health facilities is not new. Indeed, most hospitals and health centres in LMICs are awash with students

[14] The Strategic Plan noted major growth in PNFP and PFP services. In 2012, the UMoH managed 64 hospitals in comparison to 65 in the NFP sector and 23 in PFP. At Community level, the UMoH ran 1696 Health Centre II facilities in comparison to 1387 in the PFP sector and 522 in the PNFP.

[15] https://knowledge4change.org/student-placements/.

and 'volunteers' from high income countries on a variety of placement schemes. In most cases some form of payment is required either on an informal level (to individual managers) or more formally. This income is rarely if ever fed directly back into service provision.

The K4C placement model also funds both NHS and Ugandan health workers to co-work with local staff. K4C has negotiated with Fort Portal Regional Referral Hospital to invest this income in key areas of priority to the respective partners. In a unique decision, the organisations signed a PPP/H agreement that enables the partnership to underwrite the costs of materials in the Rehabilitation Facility. Subsequently, STAND joined this PPP, substantially increasing and tailoring the supply of second-hand componentry.

The national (UMoH) staffing structure identifies 6 positions for orthopaedic technologists at the FPRRH workshop. In practice only 2 are currently present in the workshop.[16] Concerned about the impact of service interventions on health worker workloads, K4C also employs 2 Ugandan orthopaedic technologists to work alongside and supervise these students. According to its actively enforced 'co-presence' principle, K4C employees and UK volunteers are not permitted to work in the absence of local staff. This is a cornerstone of our Health Partnership approach responding both to concerns about lone working and risk but, more importantly, to optimise mutual learning and prevent overseas engagement compounding existing and chronic problem of absenteeism in Uganda (Ahmed et al., 2017; Tweheyo et al., 2019).

This model has formed the basis of an MOU linking FPRRH, K4C and STAND. Having established the principles of PPP/H, the Partnership sought to identify the materials and components required to fabricate prosthetic and orthotic devices and identify relevant suppliers. In the first instance our objective was to kick start the delivery of free services to patients and capture the costs involved. The longer-term objective was to explore the potential to drive these costs down through supply chain innovation, to demonstrate the longer-term viability of this model and create an evidence-base to improve sustainability and advocate for public funding.

[16] Hospitals can use the designated funds to fill other posts according to their priorities which inevitably results in under-staffed workshops.

Which Specific Products and What Volume Are Needed in Prosthetic (and Orthotic) Fabrication?

Table 5.3 in Chapter 5 identifies the key materials used in the manufacture of a prosthetic device and the volumes of each required. This includes quantities of a hard thermoplastic (polypropylene) and foam material for padding and cosmetic finish. Both the hard polypropylenes and the softer foams are internationally outsourced as there are no local manufacturers. Polypropylene is the most expensive item both in terms of the unit cost and the weight of the product. The draping plastic comes in large 2 m by 1 m sheets (weighing 8–10 kg). One piece can be used for 8–10 patients. Polypropylene is used in the manufacture of both orthotic and prosthetic devices. The required amount is cut off the larger piece reducing material wastage.

In 2022, K4C received funding from the Tropical Health and Education Trust to trial a virtual approach to knowledge (Kenney et al., 2023).[17] The funding marked a response to the interruption of international travel during COVID-19 and growing concerns about the carbon footprint associated with international development work—and research in general. In this case, and at the suggestion of our Ugandan technologists, we sought to expose the local team to the potential for bubble-draping technology as an alternative to more traditional draping. Some of the impetus for this came from an awareness that the plastics used in bubble draping came in a much more manageable size (from an export perspective) and were manufactured in Liverpool by an SME supplier (ALGEOS). The polypropylene used in the bubble draping approach comes in smaller squares (343 m × 343 m or 406 × 406 mm) weighing 1.3 kg and 1.8 kg respectively. One piece is required per patient. The bubble draping technology also has the advantage of potentially more durable and comfortable sockets as they do not have a joining seam (Fig. 6.1).

At this point in the project, we identified and contacted a wide range of international suppliers to assess respective prices. K4C then supported the visits of 2 technologists to the UK to expose them to the materials used by the University of Salford P&O team and to visit suppliers to see the range of materials available. Samples of products were then taken

[17] Claire Horder is completing doctoral research funded by NHS England on the contribution that virtual volunteering can make to knowledge transfer in global health.

Fig. 6.1 Ugandan technologists using the draping technology

to Uganda for technologists to trial and establish a broad equivalence in quality. The prices of these products were found to vary significantly both between suppliers and, in the case of the major supplier, pricing mechanisms based on demand in different countries. Negotiations with suppliers identified the potential for significant cost reductions through higher volume purchases including 10% reductions in unit price for small volume increases (50 pieces or more) and 'negotiable' processes for higher volume orders.

Higher volume purchasing and working in a more competitive environment also enabled gains to be made through 'price-matching' between suppliers. In some cases, these gains can be quite considerable. By way of example, price matching enabled a 62% reduction in the unit price of PELITE foam. This substantiates the ATScale Market Landscaping Analysis Report that 'lack of volume orders is a key barrier for companies to expand into LMIC markets' (2021: 7). Raw material prices only tell one part of the story; the next stage was to understand the costs of getting materials to the workshops.

What Specific Costs Are Involved in Getting These Products to Public Workshops?

Although prices vary depending on companies, air freight generally costs around twice as much as sea freight. For illustrative purposes one sheet of polypropylene weighs around 12 kg. Air freight (costing £6–12 per kg) adds up to 70% to the price of commodities and delivers within a week. Shipping by sea (about £3/kg) adds only 30% but takes 3 months (Uganda is land-locked). Table 6.1 shows a simple comparison of the costs quoted by one transport company. In this case flying a small 5.46 kg weight product cost 45.5% of the overall cost compared to 31.2% when shipped (Table 6.2).

Where it is possible to ship in very large volumes (such as a whole container) these costs can be reduced to as little as £0.40p/kg. This is

Table 6.1 Comparison of flight versus shipping costs

Item	*Unit size*	*Weight*	*Unit price*	*Sea freight (£2.99/kg)*	*Total cost by sea*	*Air freight (£5.49/kg)*	*Total cost by air*
Ottobok Polypropylene 3 mm	2 m × 1 m	5.46 kg	£35.90	£16.11	**£52**	£30	**£65.90**

Table 6.2 The sizes, weights, unit prices and shipping costs for example materials (sterling)

Item	*Weight (kgs)*	*Unit Cost*	*Unit cost after Ottobock 10% Discount for orders above 30 sheets*	*Shipping*	*Total Cost before/after discount*
Ottobok Polypropylene 3 mm	5.46	35.9	32.31	16.33	52.23/48.64
Ottobok Polypropylene 4 mm	7.28	48.43	43.59	21.77	70.20/65.36
ALGEOS EVA 3MM	0.5	7.6		1.50	9.10
ALGEOS EVA 4MM	0.5	13.7		1.50	15.20

where significant opportunities lie if demand can be predicted and consolidated amongst different buyers. If demand could be predicted over a 3-month window, this could support the use of shipping rather than air freight achieving major cost-savings and environmental goals. King and Koski, unusually, allude to the environmental impacts of some of the well-intentioned but fundamentally flawed and inefficient approaches to global health; including the 'transportation of people and equipment' (2019: 2). Pazirandeh (2011) also addresses the additional environmental aspects of humanitarian sourcing advocating measures supporting 'a move towards local sourcing in humanitarian aid settings'. This, he argues, could enable shorter lead times, the development of local markets, and reduce the negative consequences of travel on natural environments (p. 377). These are laudable and increasing relevant ambitions, but they rest on the development of supply chain infrastructure.

A maze of complex and unpredictable importation costs including taxes, customs duties, inspection charges and corruption adds significantly to unit costs. Interviews with company representatives identified these not only as impacting price (and therefore sales) but also as a major component of risk leading to their withdrawal from, or reluctance to engage with, markets in LMICs.

A World Health Organisation Policy Briefing (WHO, 2021) identified 3 factors contributing to high prices in LMICs. These include disjointed markets leading to poor competition; trade tariffs on imported products; national taxation (including VAT); and dimensions of over-regulation that contribute to price escalation. Although the WHO falls short of advocating tax exemptions for products, the Nigerian Government's Priority Assistive Products List (Nigeria Federal Ministry of Health) acknowledges the contribution that high costs of importation make to the 'exorbitant costs of assistive devices' and specifically recommends exemption from tax and duties' (2022: 27).

Although VAT on whole imported Assistive Devices has been waived in Uganda, this does not apply to generic materials such as polypropylene and EVA (which could arguably be used for other purposes as building materials). Whilst the East African Community Common External Tariff document clearly identifies 'artificial joints and body parts' as zero rated (2022: Para 90.21), the situation regarding polypropylene and EVA is less clear cut. This creates problems with Revenue Authorities who try to levy VAT on these products. The 'grey area' also creates opportunities for corruption.

In addition to VAT, the Ugandan government levies a further fee of 2% to fund the National Drug Authority, even though the items are not currently listed on Procurement Planning Systems. In addition, the Ugandan Government implemented a pre-inspection charging system that requires brokers to pre-inspect even small quantities of materials prior to importation. Interestingly Uganda appointed two foreign companies to take on this role, resulting in a further 2–3% cost and significant delays. Alarmingly, both the NDA and Pre-inspection Certificate charge applies to the *whole* purchase (commodity plus freight charge). Negotiating these various charges and inspection systems is very cumbersome and time-consuming and usually involves the deployment of a chain of 'brokers' who will themselves levy fees and/or engage in forms of corruption. This contributes to the high costs passed on from Ugandan distributors to buyers and patients.

What Potential Is There to Reduce the Costs of These Products (and Services)?

At raw material stage a key opportunity exists to expose technologists to a wider group of suppliers and alternative products and enable them to try them out. This creates the foundation for competition to push prices down. The easiest way to lower costs and achieve greater environmental sustainability would be to order much larger volumes and ship these by sea. Whilst the emphasis on the 'inextricable' link between disability and poverty (Harkins et al., 2013) is important in terms of understanding the catastrophic impact of limb loss, the association may give the false impression that there is little potential for market development (purchasing power) in LMICs. This isn't the case. Demand consolidation across the mixed economy coupled with social enterprise solutions to public funding and ultimately pushing the price of services down is also a key advocacy tool in persuading the Ugandan Ministry of Health to honour its commitment to Universal Health Coverage.

Improving Procurement Processes: (2) Co-designing Audit and Forward Planning Processes

Having established a source of finance for materials purchase and a functioning public service, free at the point of use, our intervention focused on trying to predict demand over a 3-month period so that larger orders could be made and transported by sea. Danemayer et al. (2021) scoping review of demand estimation methods for assistive products found serious gaps in data notably in LMICs. In the absence of services and any accurate ways of measuring need or use of assistive devices any concrete data from medical records or large-scale surveys is patchy at best and even then, focuses primarily on vision and hearing. Danemayer's subsequent systematic review found a similar lack of coherent information on unmet AP need with the exception of vision (Danemayer et al., 2022). In the current Ugandan context, their high-level recommendations for standardisation of assistive product indicators and methods are unlikely to be taken up in the medium term. Out intervention took a rather different approach starting from the premise that need will only emerge in any tangible way once affordable and accessible services are provided. In that respect assessing need is an incremental process. And careful management of that process is required to avoid excessive demand generating unmet need or poor service experience. The process commenced with what appeared to be a fairly benign challenge, auditing existing service provision.

This ostensibly simple process—of materials and service audit—proved the most difficult aspect of the intervention. Bouchard et al. identify the lack of inventory systems and need for strong accountability mechanisms in health systems where corruption is endemic. Without these they question how workshops can 'tell the government what they really need' (2012: 7). Pazirandeh (2011) refers similarly to, 'uncertainty in demand' (2011: 365). Adding further complexity to the challenge of demonstrating need (or demand) in the public sector, key actors have a vested interested in avoiding audit especially where 'chronic pilfering' (Sekyonda et al., 2018) or 'fraud' (Bouchard et al., 2012) augments the profitability of informal private work.

Whilst many papers refer to the importance of an evidence-base and cost–benefit analysis to any form of market-shaping, achieving this in an LMIC setting is not a simple technical or capability-enhancing exercise. The lack of public procurement has undermined any motivation (or need)

to maintain records in public workshops. Our previous work on behaviour change in Uganda has underlined the importance of putting yourself in the shoes of the health worker and trying to 'imagine a different reality' where the opportunity to utilise skills exists and change can happen (Ahmed et al., 2017). Add to this the lack of IT support and access to functioning computers. The technologists in FPRRH had endeavoured to maintain patient records in hard copy for long periods when no materials were available simply recording their inability to provide services. This is a soul-destroying task for any professional.

The MOU signed by K4C and STAND initially struggled to achieve the necessary accountability to support a social-enterprise approach and generate a data-driven procurement mechanism. The culture of donation is deep-rooted; organisations and individuals in Uganda find it difficult to conceptualise an alternative approach based on a social enterprise partnership. All NGOs (and 'mzungus', the local term for Western foreigners) are regarded as 'donors' with vast reserves of cash and operating weak, parallel accountability systems. The rationale behind a single integrated accountability system linking public and NGO partners met with suspicion and resistance. Anti-corruption interventions add to the dynamics with requests for audit often interpreted as forms of 'spying'. Trust is critical to the achievement of effective partnership, especially where financial transactions are at stake, and trust is in short supply in systems so damaged by corruption.

De Vries et al. (2017) address the issue of trust in research relationships in a fascinating paper focused on water governance. They identify trust as an essential prerequisite to effective learning, knowledge mobilisation and 'transformations' in international partnerships. Trust, they argue is particularly critical to outcomes where problems are complex or contested and when actors seek to engage in co-creation or participatory processes: 'an increase in the complexity and uncertainty of scientific questions should likewise result in an increase in the democratisation of procedural rules as to how to undertake science' (p. 3). The authors conceptualise trust as 'individuals expectations about the thoughts, behaviour, and decisions of other people [and] these expectations are constantly balanced in terms of past experiences' (p. 4). Their description resonates strongly with our own experiences of trying to build the kind of trust relationships essential to support effective audit with the additional 'complexity' of working in a system tainted by corruption and where expectations have been shaped by a long history of donorism. In a subsequent paper de Vries et al.

(2018) explore the relationship between trust and the quality of communication. They conclude that face-to-face communication is necessary to achieve strong (benevolent) relationships especially when problems are complex (or 'wicked'), and tensions exist between self-interest and collective interest. We would very much concur with this perspective. Our approach has involved repeated[18] and extended stays in-country as well as Fellowship stays in the UK for members of the workshop.[19] In the absence of these we do not feel we could have achieved the level of trust to support effective accountability systems that are necessary to build supply chains.

Spending time on record-keeping is also challenging in organisational settings where no designated record keeping staff are present and orthopaedic technologists are expected to absorb this role alongside already complex, task-shifted, responsibilities. To begin to understand demand in the FPRRH workshop, an inventory system was needed that recorded each patient accessing the workshop with details of their prescription and the materials used to fabricate (or repair) each orthotic or prosthetic device. At the start of the process the orthopaedic technologists shared a fit-for-purpose 'Job Card' designed (by the Ministry of Health) specifically for that purpose, but largely unused.

Once the MOU was signed the workshop requested certain supplies. Initial supplies were provided by K4C but failures in record-keeping led to the actioning of a conditionality principle; that no further supplies could be provided in the absence of inventory data. This led to on-going 'hiccups' in supplies with stock outs impacting services. Eventually as trust built between the orthopaedic technologists employed by K4C to work alongside the FPRRH technologists and the UK-based team and a more transparent understanding of the need for data emerged, completion of the Job Cards began to happen.[20] This then complemented a running audit of materials purchased through the K4C MoU, provided by STAND, and kept in the workshop stores. Table 6.3 shows the impact of this process on the supplies of donated componentry from STAND.

[18] The value of repeat stays is discussed in Ackers (2015).

[19] Supported by the British Commonwealth Professional Fellowship scheme and K4C funding.

[20] Limited compliance by some staff is a continued problem reflecting some of the challenges of human resource management in the Ugandan public sector.

Table 6.3 Receipt of donated components from STAND

		Oct-2021	*Jan-2024*
Adult	Right foot	15	97
	Left foot	12	107
	Knee joints	6	95
	Connectors	14	247
	Socket adaptors	10	175
	Pylons	30	187
	Thigh corset	1	108
Children	Right foot	2	4
	Left foot	5	0

Table 6.3 shows the growth in volume of donated components from STAND as the PPP has evolved. As noted earlier we faced some initial problems in establishing the necessary accountability systems required both by STAND (for its own suppliers of free componentry) but also to support the ability to project demand over a 3-month period and support higher volume and more targeting supplies. Prior to 2021 the only donations were received in small numbers and on a very random basis via the National Referral Workshop. On occasions components were sent that were not of use to the workshop team. In the Ugandan public sector this causes more problems than we might anticipate as recipients are required to store all donations, often including those that are damaged, for fear of accusations of theft. Investments by STAND in the UK has led to improvements in their own accountability systems, in close conversations with and tailored to the needs and resources of teams in the LMIC settings. Integrating these systems within the national recording systems has improved accountability overall and supported significant improvement in supply systems. To support his process, K4C now receives the components, checks the consignments against the packing list and stores them in a dedicated store. It then distributes components to the workshop on a 'just-in-time' basis and feeds back to STAND both on volumes used and any issues regarding the quality of components received.

In 2023 STAND introduced a new on-line system to capture how its components are used including some of the characteristics of patients. The technologists enter the data on a slider (Fig. 6.2).

Figure 6.3 summarises the 39 cases that received a STAND componentry from 1st Jan 2024 to 19 June 2024 and presents this on their website. This system not only provides accurate data for their funders but

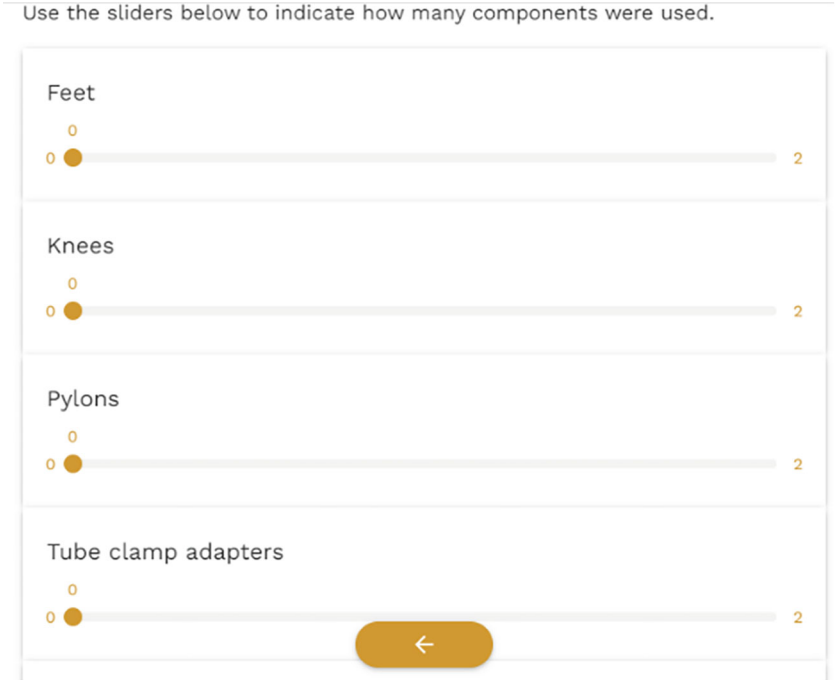

Fig. 6.2 Screen shot of STAND on-line system (1)

also improves efficiency as stock levels are automated from the usage and prosthetic limbs manufactured 'feet on ground').

At the present time the workshop is able to provide monthly audits of stock and patient cases, and a simple algorithm has been developed to calculate materials from the cases. We have underlined the *process* aspect of this intervention. The outcomes at this stage in the developmental process include partnership compliance in continuous audit. This is now facilitating a procurement planning system capable of larger volume, quarterly orders and shipment by sea freight.

As the issue of predicting demand ahead of time and in greater bulk (to take advantage of shipping costs and benefits) became more salient this raised the issue of storage and waste disposal. The workshop lacked storage space due to a stockpile of unusable components and parts left from previous funders and damage to some components due to high levels of humidity. Storage of larger quantities also created additional audit mechanisms and risks. On this basis Knowledge For Change made the decision to allocate storage space at its headquarters, close to the hospital. This has supported a simplified accountability system with the hospital able to order on a 'just-in-time' basis (Table 6.4).

The impact of this supply chain development on the costs of manufacturing a typical below knee prosthetic device can be seen in Table 6.5. The reduction in the prices of locally available ubiquitous products was due to shopping around with some price inflation (on rivets).

Table 6.5 shows a reduction of 46% in the costs of materials required to assemble a below knee prosthesis when the bespoke componentry is provided by STAND. The 2021 figure aligns with the charges users reported being quoted from FPRRH prior to intervention (Fig. 5.4 in Chapter 5) but is significantly cheaper than those cited at Mulago which also had access to componentry.

Intervention Outcomes

Expansion in the Volume and Geography of Patients

As the Public–Private Partnership intervention progressed and audit mechanisms gradually improved supplies of both second-hand componentry from STAND and the materials needed to manufacture devices using these increased. This is reflected in a gradual growth in service provision. The number of patients attending the FPRRH workshop

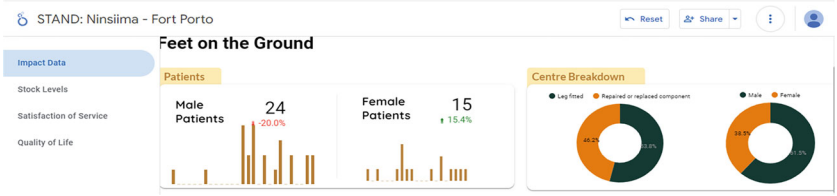

Fig. 6.3 Screen shot of STAND on-line system (2)

Table 6.4 The impact of the intervention on material costs

Product	*Quantity*	*2021 (prices from local distributors)*	*2024 (direct procurement)*	*Price reduction (%)*
Polypropylene 3 mm	1 sheet	£112.73	£75.39 (same manufacturer)	33.12
EVA Foam 3 mm	1 sheet	£37.69	£13.61 (new manufacturer)	47.97
Stump Socks	Pack of 10	£124.30	£37.90 (new manufacturer)	69.51

Note The prices indicated include a profit margin (of 20%) to cover the costs of running the social enterprise and promote sustainability

Table 6.5 The impact of price reduction on the costs of manufacturing a below knee prosthetic socket

Material	*Quantity*	*2021*	*2024*	*2024 Social enterprise*	*% Reduction*
Generic Items: procured internationally					
Polypropylene 3 mm	¼ Sheet	28.18	23.48	18.85	19.72
EVA 4 mm	1 sheet	37.58	31.31	18.6	40.59
Stump Socks	1	12.43	12.43	3.79	69.5
Price reduction			**67.22**	**41.24**	
Ubiquitous Items: procured locally					
POP Powder	10 KG	6.26	5.85	5.85	0
POP Bandages	6 Pcs	3.76	2.66	2.66	0
Glue	500mls	2.51	1.96	1.96	0
Rivets	4 pairs	0.84	0.84	1.04	−23.81
Total cost		**£91.56**	**£66.10**	**£52.1**	

showed a significant and steady increase from 2021 to 2023. In 2021, 176 patients were recorded. This number rose by 33% in 2022, reaching 234 patients. The upward trend continued in 2023, with a 22% increase from the previous year, resulting in 286 patients. The progressive growth in patient numbers reflects the positive impact of the intervention, making

essential prosthetic and orthotic services more accessible and addressing previous barriers such as financial constraints and lack of materials.

In 2024, 311 patients attended the workshop which indicates a significant number of patients turn-up. The uptrend continues, the total for 2024 surpasses the previous years with an 8.7% increase. The data indicates a successful intervention leading to a steady increase in patients attending the FPRRH workshop from 2021 to 2024 attracting patients from both local and far districts. This partly shows that FPRRH is becoming a preferred centre for prosthetics and orthotics services.

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Table 6.6 shows trends in patient characteristics over the three-year intervention period. During that time 696 people received a service at FPRRH Orthopaedic Workshop. Just over half (54.6%) of all cases involved children aged 15 and under. Women and girls were underrepresented in both age groups; women formed 44.6% adult users and girls formed 42.4% of child users.

Table 6.7 shows the type of service these patients received.

The majority of users (78% or 356) receiving new devices had a lower limb injury or deformity. Upper limb cases were less common comprising

Table 6.6 Characteristics of the user population attending FPRRH orthopaedic workshop 2021–2024 by age group and gender update

Year	*Gender*				*Total*
	Male adult	*Female adult*	*Boys under 15*	*Girls under 15*	
2021	40	46	53	37	176
2022	69	39	67	59	234
2023	66	56	99	65	286
2024	107	67	62	74	310
Total	282	208	281	235	1006

Table 6.7 Characteristics of the users receiving prosthetic and orthotic devices from FPRRH orthopaedic workshop 2021–2024 by device type update

Year	*Lower limb*		*Upper limbs*		*Spinal orthotics*	*Repairs*	*Total*
	Prosthetics	Orthotics	Prosthetics	Orthotics			
2021	38	66	9	3	19	41	176
2022	41	64	14	3	11	101	234
2023	50	97	3	32	7	97	286
2024	55	99	16	9	10	121	310
Total	184	326	42	47	47	360	1006

Table 6.8 Characteristics of the users receiving repair services from FPRRH orthopaedic workshop 2021–2024

Year	*Prosthetic repair*	*Prosthetic repair (foot replacement)*	*Orthotic repair*	*Walking aid repair*	*Total*
2021	19	3	18	1	41
2022	28	8	61	4	101
2023	25	15	52	5	97
2024	40	7	71	3	121
Total	112	33	202	13	360

14% cases (64). Spinal orthotics made up 8% (37 cases). The workshop also handles device repairs and adjustments (Table 6.8).

Ninety-five per cent of orthotic repairs (124) involved lower limb cases and mainly the replacement of Velcro strapping: 5% (7) involved replacing strapping or rivets on spinal orthotics and 26.5% (26) of prosthetic repairs involved foot replacements. The remaining 73.5% (72) involved height adjustments, screw replacements and joint repairs.

Table 6.9 shows a breakdown of orthotic cases by age category showing the predominance of children amongst orthotic users (86%):

Distances Travelled as an Indicator of Patient Satisfaction

Chapter 4 discussed some of the limitations of the donor-sponsored outreach approach to rehabilitation service delivery and the emphasis this approach places on Type 2 Delays (delays caused by difficulties associated

Table 6.9 Provision of orthotic devices by age category (2021–2024)

Year	*Orthotics breakdown*	
	Adults	*Children (Below 15)*
2021	10	59
2022	8	59
2023	19	110
2024	23	85
Total	60	313

with physically accessing services). There is a powerful common-sense logic to this approach particularly when we are dealing with people who are themselves physically disabled and thus face additional mobility challenges. In an ideal world service would be provided as close as possible to citizens. Huck et al. found that people with major limb loss, even in the post-conflict areas of Northern Uganda, are spatially distributed rather than clustered as was previously believed to be the case. On that basis they calculated that a user would have to travel an average of over 60 km to access public services (up to a maximum of 170 km), concluding that, 'it is unlikely that many people with MLL will be able to travel the required distance to receive services using traditional 'centralised' models based in the cities' (2022: 377). Our own qualitative data would challenge this assumption and suggest that people with MLL can negotiate the geographies involved with many reaching well beyond regional catchment zones when quality services are available and free. Having said that, we do not have data to show how many people were unable to make this journey.

Where there is a need to develop sustainable and cost-effective services in a context of severe resource constraint certain 'trade-offs' are required. The growing success of the intervention can be seen not only in increased patient or service volume but also in its growing geographical reach suggesting that, where services are provided in a predictable, respectful way, at no cost and to high quality many (perhaps not all) patients can plan ahead and overcome transport barriers.

Table 6.9 and Fig. 6.5 evidence the distances users have travelled to access free public prosthetic services at FPRRH. Figure 6.4 shows a growth in users living locally (within 10 km) and medium and long distances.

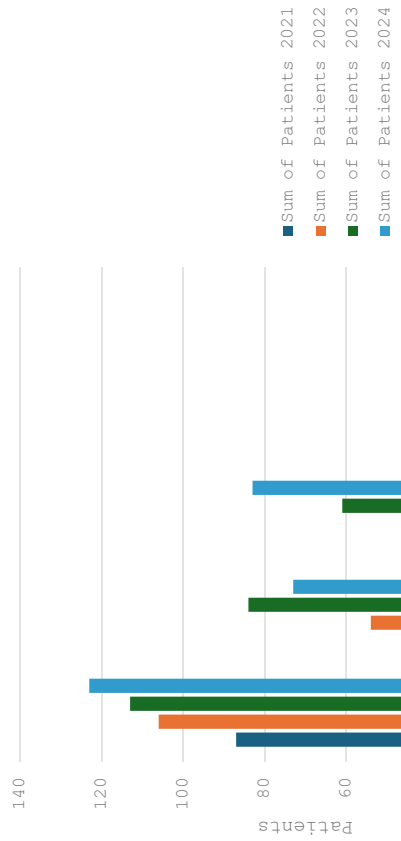

Fig. 6.4 Summary of distances travelled by users as services developed[21]

[21] As noted, the intervention began to impact services in mid-October 2021.

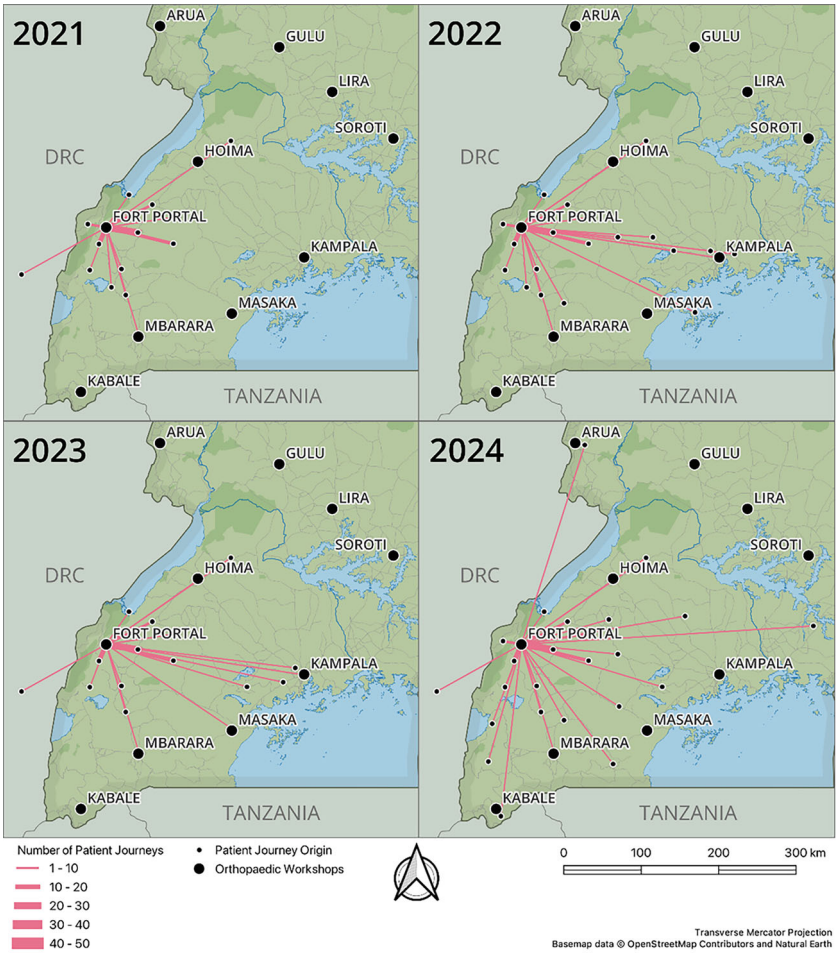

Fig. 6.5 Map showing the Journeys of Patients Attending Fort Portal Workshop in 2021, 2022, 2023 and 2024 respectively

Figure 6.5 map the same data to give a more visual presentation of distances travelled. This also enables the reader to see how users are bypassing more proximate public orthopaedic workshops including those in Mbarara, Mubende, Hoima, Gulu, Moroto, Jinja and the National Referral Workshop (Mulago[22]). The data for the first 6 months of 2024 shows some users making even longer journeys from Kakumiro and Arua (over 490 km by road).

Patient Satisfaction[23]

The interviews with users included a question about their satisfaction with the services received in FPRRH. Interviews were conducted by two prosthetic users one of whom was also a service provider.

The findings overall suggest that the service provides high quality prosthetics in an environment of respect and care. Nearly all patients described how shocked they were to find that services were entirely free:

> The service here is good. Being able to come here and get the services I need. There are free beds here and I can sleep well. The beds here are better than the ones I have in my home. Yes, I have to buy my own food but it's what I would do even if I was home, so that is not a problem. They make a leg for you free of charge. This is not something which has ever happened that somebody would get a leg free of charge. (2)

Many patients referred to the kindness and professionalism of the staff which, once again, seemed to come as a surprise:

> The doctors[24] welcomed me very well. They told me all the procedures and gave me a day to see them again. (10)

Our previous work in the area of maternal health emphasised the importance of respectful care to health seeking behaviour in Uganda (Ackers

[22] Mulago has received larger volumes of componentry from STAND over that time period and some support from the Hospital with materials.

[23] The following section summarises a report prepared by K4C for the Ugandan National Rehabilitation and Assistive Technology Strategic Planning Team https://knowledge4change.org/wp-content/uploads/2024/12/Patient-Satisfaction-with-Services-at-FPRRHs-Orthopaedic-Workshop-2021-2024-v1.7.pdf.

[24] Patients refer to orthopaedic technologists as doctors.

et al., 2018). It also raised questions about the concept of respect in different contexts. In Uganda patients placed an emphasis on the impact of corruption and over-charging as a dimension of respect. The respondents in the current study echoed this: '*Here even the doctors have love for patients*' (55) and, '*They are really caring people*' (25). Clients also reported a sense of being listened to which empowered them to express their feelings:

> Other hospitals do not treat us as well as we are treated here. The technicians here listen to our needs and put them into consideration when they make the limbs. It is not the same in other places I have been to. Sometimes patients can tell doctors that the leg is too tight or painful or short, but they don't listen. Here these people have become our friends, and we are free to tell them how we feel. (31)

The patient in the next case had previous experience of Mulago hospital.[25] As he lived in Mukono near Kampala the interviewer asked him why he decided to come to FPRRH:

> It is very difficult to get help there unless you have money to give to people who can help you to get the service. There is an expectation that you need to bribe people to help you access or even give you directions. Sometimes patients there may give money to fraudsters who do not even help them in the end. (38)

The previous discussion about supply problems in under-funded public workshops explains the common reference to supply issues. As the interviews captured users attending the facility over a 3 year period and when the intervention was developing it is not surprising that some patients noted delays due to materials shortages. A common concern expressed by patients was the delays they experienced either in accessing services in the first place or extending their residential stays as a result of shortages of materials:

> I came here but they told me there were no materials and that they no longer ask people to buy materials so they said I should wait until they call me when the materials come. I waited for their call, but they could

[25] This story is echoed many times in the Report on patients' experiences of amputation.

> not call me, so I called inquiring whether the materials came, and he said yes materials are there. Please give my thanks to Knowledge For Change for the good work, because before I knew every 3 years, I have to spend 80,000 shillings buying a plastic shoe but now I can get it for free. (18)

The user went on to ask how long this free service was likely to continue (perhaps accustomed to the short-term nature of much foreign funding) and also, if other devices were available:

> How long will this organization support this workshop, and do they also give pieces of equipment like crutches that can support me when walking and maybe wheelchairs for people that can't walk?

In the next case the patient was in prison when a prison officer advised him that the workshop could provide artificial hands. On his first visit he was advised that they lacked the components to make a prosthetic arm. Sometime later he was offered a range of options (funded through the Koalaa program):

> They gave me different hands to choose from and I chose one. (05)

As noted previously cosmesis is very important in Uganda and users are keen to access covering materials (EVA) in a dark brown colour that is currently not available through the less expensive suppliers. Users were often waiting for the cosmetic coverings for their prosthetic legs:

> I am already with my new leg but only that this leg is not covered, and I would like to go home when it is covered as the materials for covering the leg are not yet here. (20)

On-going improvements in accountability and supply chain systems have reduced periods of stock-outs.

Despite the fact that the services are managed and delivered by Ugandan staff, it is disappointing to see continued reference to 'whites' and 'sponsors' in some of the users responses reflecting their prior experiences and expectations that free public services are always associated with donors:

> We are happy that we have a sponsor to buy materials in our workshop in Buhinga. I had lost hope of ever getting a prosthesis. (31)

One of the impacts of materials shortages is that patients may suspect corruption or charging (seeing this as an excuse) and this puts pressure on staff to justify shortages. One patient describes how he had, '*mixed thoughts at first - I thought the technicians wanted money from me but feared to ask directly because they kept telling me they had no materials. At some point, I wanted to ask whether they could make me a leg if I paid them some money, but I did not have it at the time. I honestly could have given them money if I had it just so I could get a leg. Materials were the only hindrance*' (42).

It is interesting to see that in this case (and others) patients sometimes expressed a willingness to contribute to costs to expedite services. A focus group with several women who had to extend their stay due to the lack of plaster of Paris exposed some real concerns that they would be punished by their husbands for staying away longer.[26] The women were very keen to pay for the POP but under the Ugandan system this is not permissible (despite the lack of UMoH funding). In the following case the woman still assumes a donor (sponsor) approach whilst requesting the right to make a personal contribution to expedite service delivery:

> We do not expect the sponsors here to be perfect but if there are supplies like chalk that they cannot provide for us in time, we are willing to contribute some money to quicken the process. In the spirit of cooperation, the hospital can ask us to contribute some money, like 20,000 shillings to buy the chalk. We are the ones who need legs, and the delays affect us most. We can buy this chalk instead of spending money and time here. We can ask our families to raise that money together. (1)

The availability of in-patient beds to support genuine rehabilitation is a unique feature of the FPRRH Workshop and avoids some of the limitations of traditional donor 'outreaches'. This does imply a cost to users though both in terms of cash (for food) and also the loss of earnings for users and/or their attendants.

Whilst the user (2) above suggested that finding food was no greater challenge than it is at home, this was not always the case. This may reflect the fact that they are some distance from their own gardens and local food or, in some cases, the fact that they are male and did not have attendants (and were unable or unwilling to cook for themselves):

[26] This issue was discussed in Chapter 2.

> The only problem I have observed here is hunger. We get so hungry. When you have money you use it, and it gets finished and even the food here is not easy I had come with 100,000 and it is done.
> Q: You still have some more time here because you have not yet trained?
> I have 2 more weeks. I have called home they also do not have money. (51)

In some cases, patients were anxious to leave early as a result of these costs and even against the advice of the technologists who are keen to optimise rehabilitation:

> I have had the leg for three weeks. I feel ready to go home now.
> (Technologist) We expected him to be here for two months, but he says that he wants to go home now because he does not have enough money. We have not yet given him the proper instructions. We have also not yet done the cosmetic part since we are lacking materials. (39)

Waiting for materials to arrive puts considerable pressure on individual and family budgets:

> The church is paying the money I use for food. I have run out of money. I am practically begging but cannot leave this place without a leg. The services here are good and the fellow patients are treating me well. We share food and plan to make ends meet. I am disappointed that the doctors lack some materials to make the leg. (41)

Delays in accessing POP occurred at an early stage in the PPP/H process when there was some resistance to the accountability mechanisms put in place. This led to temporary delays in supplies.

Some users expressed disappointment with their devices. This in no way reflected on the skills of the technologists or, in many respects, their access to common technologies in Low- and Middle-Income Settings. Rather, it reflected the common experience of raised expectations particularly in the case of upper limb prosthetics and, more recently, those with amputations above their elbow joints:

> I had a couple of prosthetic hands (before) so this lowered my high expectations. But I hope (this hand) will help me have a better cosmetic look and be able to hold some items. I used to expect to have a prosthetic hand

> that can help me cook very well, hold different items and go back to my driving that I had started before the accident. (9)

The problems experienced by this patient are currently being addressed with the support of the University of Salford Upper Limb Prosthetics team. Double amputees also face specific challenges. Whilst very satisfied with the prosthetic services one user (10) requested the provision of a wheelchair. Unfortunately, in the Ugandan system, this is a service only (nominally) provided at the National referral workshop.

It was interesting to see how many respondents referred to the lack of awareness of services—and specifically their ability to access free public services at FPRRH. Many urged the team to improve public awareness so that others could benefit from the services:

> There are some other people like me in my village. Can they also get help? (04)

Urva et al. (2023) analysis of patient and provider perspectives on prosthetic services in Tanzania deployed a very similar methodology to our study and captured similar points about very poor levels of service awareness. They cite a local prosthetist working in a regional referral facility who suggests that 'out of 100 people at the Ministry of health, maybe 2 or 3 are aware of our department and what we do' (2023: 4).

With the exception of the upper limb study outlined in Chapter 7 the research team did not go out to seek patients. This was a deliberate strategy to capture the impact that service development had on user volumes and experiences.[27] In most cases users described how they had found out about the services from friends or contacts with health workers or, as in the following case, by seeing someone using a prosthetic device:

> I started selling children's shoes (and saw a man) who uses an artificial leg. The man asked me whether I also need the leg? I told him yes so; he told me that he got the leg from Fort Portal Regional Referral Hospital, and he got it free and was using it. I couldn't believe it as I had tried getting one but failed and I knew it was expensive. I got a bus from Mityana, and

[27] K4C is now paying greater attention to awareness-raising albeit carefully through accessing referral facilities. A more general campaign involving for example radio advertising could overwhelm the facility and reduce patient care. Our experience here builds on an awareness-raising campaign to promote cervical cancer screening (Auma et al., 2023).

> they assessed me and told me that I must do some exercises so my leg can stretch well (before making the artificial limb). (11)

In the following case the patient suggests that even hospital staff were unaware of the service and where it is located:

> I came through the lower [main] gate because this was the first time to come. I sat there for a few seconds, and somebody asked me what I came for. I don't think the person knew about the services in this workshop. I said I had come to the workshop to get an artificial leg. The person directed me to go to Outpatients and a gentleman there told me to go to the workshop. I took a motorcycle to the workshop. You need to campaign and spread the word about these services. There are many people especially in the villages who need these services, but they do not know where and how to get them. Some may not know that they can get a leg. Others who do, think they must pay from their pocket. There are so many disabled people who need legs, but they cannot afford. I was very lucky that the doctor told me about this place and especially that the legs here are given for free. If the doctor did not tell me this, it would have taken me at least 2 years to get a leg or even fail because it is very difficult to raise money. This was the first place I was told about, and I trusted him when he said that I could get the leg for free. (48)

In another case it was a chance link with a cleaner at the hospital that made the patient aware of the services (43). The following patient heard about the service from a colleague who knew a doctor at FPRRH. His case illustrates a number of points about service awareness including:

1. The **existence of** the orthopaedic workshop in FPRRH
2. The fact that services are **free** to the public.
3. The importance of the **extended rehabilitation** stays to patient outcomes
4. Awareness that prosthetic services are available to **above knee** amputees.

> My colleague whose truck caused the accident told me about this place. He has a brother who is a doctor in this hospital who said I could get a leg here. I told my friends about it and that the legs here are free, but they doubted. They did not expect me to get a leg here and suggested I go to Kampala. I am looking forward to spreading the news about this place

> to my friends in Hima. I want to prove to them, be the visible example, that getting a free leg in a government hospital is possible. I am saddened because very few people know about this.
>
> When my stump was below the knee, I was hopeful that I could get a leg after recovery but when the third operation was done [above knee], I assumed that there were no legs for above knee amputees. The only amputee I met with a limb was below the knee, so I assumed that there were no above-knee devices and my fate [never being able to walk] was sealed. (46)

The man in the next case was amputated in FPRRH and advised by the medical team to return. This is a good example of service integration that we are now beginning to see in the hospital. He describes how the technician, '*counselled me and reassured me that they would make me a leg and help me get walking again. After assessing me and taking measurements, they asked me to go home and let the stump heal before attempting to fit a new leg. I returned after 3 months. They gave me a leg and did training with it for about 3 months*' (42).

Conclusion

This chapter has evidenced the progressive changes achieved over the course of a 3 year intervention period. Improvements in accountability systems and international scoping of suppliers and transport have significantly reduced the underlying costs of providing prosthetic services. This represents an immediate benefit to the FPRRH Health Partnership driving down costs to improve the long term sustainability of the workshop. The data presented shows not only a progressive growth in the volume of patients but also the widening of the catchment area. The interviews with patients demonstrate the positive experiences of service users. FPRRH is the only public workshop in Uganda delivering free and universal health coverage in rehabilitation services. The service model is based on a pioneering Public–Private-Partnership in Health mechanism capable of sustainably providing services in the long term.

CHAPTER 7

Digital Technologies to Support the Building of an Evidence Base on 'What Works' in Uganda: A Case Study in Upper Limb Prosthetics

Abstract This chapter addresses the neglected issue of upper limb prosthetics. It uses a case study of an evaluation of a novel prosthesis, the Koalaa ALX system, to illustrate how clinicians and commissioners of services in Uganda and other SSA countries, might swiftly and at low cost, gather evidence for 'what works'. The evaluation involved a combination of qualitative methods with objective data on both physical behaviours of the participants and their patterns of prosthesis wear. We discuss the potential for similar approaches to be used in other contexts, and for evaluation of other devices.

Keywords Upper limb · Prosthetics · Digital outcome measures · Innovation · Evidence base building

The study discussed in this chapter was carried out by a team comprising Nico Pickard, Benedict Mulindwa, Lauren Gracey-McMinn, Malcolm Granat, Alix Chadwell, Sam Curtin, Dave Howard, Louise Ackers, Robert Ssekitoleko, and Laurence Kenney.

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Introduction

In Chapters 4 and 5, we outlined the highly complex rehabilitation landscape in Uganda, characterised by poorly resourced and fragmented services, including public sector workshops which receive no funding for materials or components. We noted that the Ugandan Ministry of Health (UMoH) has drafted its first Rehabilitation and Assistive Technology Strategic Plan and recognises the need to address the complete absence of funding for rehabilitation services and is in the process of developing a list of priority assistive technologies. Going forward, the willingness of the government to create policy and promise to deliver on its commitments in the Assistive Technology (AT) sector, suggests there may be a receptive audience for a high-quality evidence base to inform future policy decisions. One question is how to collect such evidence, swiftly and at relatively low cost.

In this chapter we will begin by highlighting a point made in earlier chapters, namely the tendency of donors and providers of prosthetics services to focus on the needs of lower limb amputees, often to the exclusion of those with upper limb absence. The main focus for this chapter is a study which tested the introduction of a novel upper limb prosthetic technology, the Koalaa ALX system via the Fort Portal service. The Koalaa system, by contrast to most other prosthetic devices, avoids the need for the time-consuming and complex fabrication of bespoke sockets, challenges to the manufacture of which have been discussed at length in the earlier chapters. The study, for the first time, captured objective data on both real-world use of the prosthesis by users and concurrently, their free-living physical behaviours, including community participation. The study results are submitted for publication elsewhere (Pickard et al., 2025, in review) We focus here on the value of the methods, in the context of the almost complete absence of empirical studies of prosthetics devices in the Ugandan (or other Sub-Saharan African) contexts. Such data, which could be collected at scale, and at an acceptable cost, may be of value to NGOs and other service providers, including the UMoH, to better inform their allocation of scarce resources. We conclude with a discussion on the potential for such methods to be used in other contexts.

Upper Limb Absence

As this chapter reports on a study of a new device for upper limb (UL) amputees, it is worth discussing what is known about the potential demand for such devices. (McDonald et al., 2021) found that 38% of the total global population of traumatic amputees experience either unilateral or bilateral upper limb absence. There are a small number of reports on prosthetic service provision in low resource settings, which give a detailed breakdown of patient populations by limb absence level. For instance, Dickinson (Dickinson et al., 2022) reported on an audit of service provision, from 2005 to 2019 in three clinics in Cambodia. They found that the distribution of patients presenting at the clinic reflected the socio-political history of the country, with limb absence primarily due to weapon-related trauma dominating cases prior to 2000, with a shift towards non-communicable disease and road traffic accidents evident in recent years. Just over 6% of the 7117 prosthetic devices supplied were to people with upper limb absence at the trans-radial or trans-humeral levels.[1] A report by Berthaume and colleagues (Berthaume et al., 2023) reported on service provision from 1987 to 2018 at a clinic in the Jaffna region of Sri Lanka. This clinic also served a population which suffered from major conflict over the reporting period, and they found that around 7.5% of the 2364 reported amputations were of the upper limb. Interestingly, they also reported that just under 4% of the 7005 prosthetics prescribed were upper limb.

Precise numbers on the demand for upper limb prosthetics in Uganda are not available, but likely the most robust prevalence study reported that around 0.5% of the population of the Acholi region of Uganda live with major limb loss and of these, around 39% live with upper limb absence (Huck et al., 2022). However, data from this region is not likely to be representative of the broader Ugandan population, as Acholi experienced a significant and prolonged armed conflict, the results of which are seen in the amputee demographics. A retrospective analysis of medical records from three Ugandan regional referral hospitals found that upper limb amputation accounted for 14.2% of cases (Mulindwa et al., 2024). While this is a lower figure than the estimates by McDonald (McDonald et al., 2021) or Huck (Huck et al., 2022), it still represents approximately one in every seven cases.

[1] Below elbow and above elbow respectively.

As can be seen in earlier chapters, the interventions implemented in FPRRH have had a demonstrably positive impact on the prosthetics and orthotics services, but most of the beneficiaries of this have been lower limb amputees and people requiring orthotic interventions. The reasons for this are complex, but one key driver is that the high value, bespoke components which are pivotal to assembling a prosthesis largely come from donations from STAND. As an organisation STAND focuses on lower limb absence. This focus is not unusual. Indeed the WHO priority list of assistive devices published in 2016, included lower limb prostheses, but did not include upper limb prostheses (WHO, 2016).

Device Abandonment and Repair

A long-standing issue for providers of, particularly upper limb prosthetics services, is device abandonment. Even in well-resourced settings, the abandonment rates of upper limb prostheses have remained stubbornly high; a recent study reported rates of 44% (Salminger et al., 2022), and found that these appear to have not changed much over recent decades, despite advancements in technology. These figures have been captured through well-designed surveys, all carried out in high resource settings, including the UK/EU (Salminger et al., 2022), Canada (E. A. Biddiss & Chau, 2007a; E. Biddiss & Chau, 2007b), and the US. Common factors linked to abandonment include comfort, and the limited function offered by current devices (Smail et al., 2021). However, to the best of the authors' knowledge, there are no data on upper limb prosthesis abandonment rates in low resource settings (Dizon et al., 2024), including Uganda, and it is interesting to speculate on factors which may lead to either higher or lower abandonment rates than seen in high resource settings.

One particular issue which may lead to the recipient stopping using their prosthesis is (lack of) access to repairs. A recent study in Tanzania, focusing on above-knee amputees identified concerns around the longevity of devices, and challenges in accessing repairs (Urva et al., 2023). Other studies in high resource settings have suggested people sometimes avoid using their device, out of fear of damaging it, and the associated cost of repair (Franzke et al., 2019). As outlined in chapter four, donor-led outreach camps to distribute prosthetic devices are common in Uganda. Although the nature of the camps varies, one of the key metrics for donors (number of limbs delivered) would be

negatively impacted if their staff also offered repair and maintenance services, suggesting it may not be in camp organisers' interests to offer such services. Indeed, the practicalities and costs associated with overseas donors offering long-term support are likely to rule out this option. It is unsurprising that we found that none of the interviewees who had received upper limb devices through outreach camps reported having accessed repair and maintenance services offered by camp organisers. Although we know that informal repair, often by the individual themselves, is a common route (Oldfrey et al., 2023), in some (perhaps many) cases, this may not be possible. In these cases, 'involuntary abandonment' is the likely outcome. Finally, the FPRRH workshop relies heavily on second hand components donated from high resource countries. Such devices are almost certainly designed for high income settings[2]; we simply don't know how robust these devices are to the wear and tear seen in, for example, Sub-Saharan African settings.

Appropriate Upper Limb Technology for the Ugandan Setting?

The concept of appropriate technology echoes the language of a much older concept of 'intermediate technology'. Harkins et al. (Harkins et al., 2013) note the reference to appropriate technology in their literature review of P&O services in LMICS but conclude that there is no consensus on what constitutes appropriate technology. On the one hand papers suggested that imported technologies from industrialised countries require regular maintenance and are not designed for the environment or lifestyle needs of disabled persons in LMICs (2013: 357). On the other hand, 'indigenous devices are often regarded as primitive' and may not meet the needs in terms of cosmetic finish.

Over the last decade or two a large number of engineering labs have published designs for 'low cost' prosthetic hands. A search on Google Scholar for 'low-cost' AND 'prosthetic hand' produced over 6000 results, almost 3000 of which were published in the last 4 years. Many of these exploit a combination of 'hobby'/consumer electronics (e.g. Arduino) and/or additive manufacturing. As highlighted by TenKate and

[2] Later in this chapter we report on an emerging shift in focus in the sector, characterised by a small number of innovative start-ups, with products designed for, and in one or two cases, tested in, low resource settings.

colleagues (Ten Kate et al., 2017), it is far from clear that additive manufacturing is the best or cheapest method of manufacture for upper limb prostheses. These studies also tend to be predicated on the idea that component cost is the key criteria to consider, and rarely discuss the issue of maintenance and repair. More importantly, the authors could not identify a single paper reporting on the testing of any of these devices, in a sub-Saharan African country.

As outlined above and in previous chapters, the high value components entering the Ugandan public sector prosthetics services largely come via donations. It is reasonable to assume that electrically powered upper limb devices, such as myoelectric prostheses, are unlikely to be suitable for most people in Uganda, in part due to the need for access to specialist (typically, offered by the manufacturer) repair services (Nagaraja et al., 2022). Also, it is notable that user manuals for most of this type of device emphasise, for example, the need for users to avoid heavy duty activities, which may not be a realistic option for most Ugandan users (Davidson et al., in preparation).

With regard to what would constitute an 'appropriate' technology for the Ugandan setting, it is generally accepted that co-design with potential users can lead to better assistive products (Gavette et al., 2024; Jones et al., 2021). However, there has been remarkably little work exploring the lived experiences, and/or user needs amongst upper limb absent populations in Sub-Saharan Africa, and even less work attempting co-design with this population. In our Fit-for-purpose prosthetics project[3] which focused on the design of purely mechanical upper limb prosthetic devices, we carried out one of the first studies to capture the perspectives of people with upper limb absence living in Uganda (Morgado Ramirez et al., 2022; Ramirez et al., 2025, in review). We also carried out one of the first co-design studies in Uganda, with a group of people living with upper limb absence (Hussaini et al., 2023), finding that, when making informed choices, people favour a balance between good cosmesis and function and were prepared to sacrifice a degree of each characteristic in order to achieve this outcome.

We started the Fit-for-purpose prosthetics project, with partners in Makerere University, in 2018 with the intention of designing novel, purely mechanical upper limb prostheses, which we hoped in the longer

[3] GtR (https://gtr.ukri.org/projects?ref=EP%2FR013985%2F1).

term could be manufactured locally. In addition to the concerns about local manufacture raised by Harkins (Harkins et al., 2013), on reflection, we were also perhaps a little naïve about the challenges to deliver on this goal, given the current state of the medical engineering sector in Uganda. For example, the medical device regulatory environment is poorly structured, IP protection is expensive and difficult to implement and there is little access to venture capital to support scale up of start-ups (Matovu et al., 2023; Nakandi et al., 2023). While initiatives, such as the AT2030 programme are starting to address some of these issues globally, through, for example, accelerator programmes,[4] there is little evidence of similar activities in Uganda.

However, as the project developed, and as the WHO's GATe initiative (Khasnabis et al., 2015) started to impact on manufacturers, the landscape began to change, with a small number of start-ups in the UK and elsewhere starting to focus on 'appropriate design' of prostheses. A good discussion of emerging products can be found in (Liao et al., 2020). Examples of lower limb devices include D-Rev's ReMotion Knee, the LegWorks All-Terrain Knee and the knee joint from Go Assistive Technology. All of these products are relatively low cost, but what appears to differentiate at least some of them from other devices is their attention to the context within which they will be used. For example, Go Assistive Technology's knee joint was designed based on user requirements captured during studies carried out in two low-resource settings, Tanzania and Cambodia. Below, we introduce a technology produced by Koalaa, another company with an explicit interest in offering their product to consumers in low resource settings.[5]

[4] Innovate Now—Africa's 1st Assistive Technology Venture Accelerator (https://atinnovatenow.com/).

[5] See, for example Helping hands: The incredible power of assistive technology (https://www.bbc.co.uk/mediaaction/where-we-work/africa/sierra-leone/helping-hands-prosthetics/).

Prosthetic Sockets and the Potential Impact of an 'Off-the-Shelf', Adjustable, Socket on Services

An area that has received relatively little attention in research, and yet remains a major challenge to the delivery of fit-for-purpose upper limb prosthetics in any setting, is the design and fabrication of comfortable sockets. With the exception of prostheses which are directly attached to the skeleton (so-called osseointegrated devices), all prosthetic limbs connect to the residual limb via a prosthetic socket (Fig. 7.1). Sockets are almost all single bespoke structures.

Although digital scanning and 3D printing of sockets is used in high resource settings, the process still requires skilled input from the clinician to translate the scan of the surface geometry to the required shape of the

Fig. 7.1 Prosthetic socket fabricated at the Fort Portal Regional Referral Hospital workshop

socket (Olsen et al., 2021). Bespoke CAD software packages designed for prosthetic socket manufacture are required and these are typically expensive. The evidence base to support the use of 3d printing of sockets is sparse, with a notable lack of high quality studies of commercially available 3d printed sockets (Oldfrey et al., 2024). A small number of papers have reported on 3d printing of sockets in low resource settings, e.g. (Ratto et al., 2021)but these studies are small scale in nature and none have been identified that focused on the upper limb. As mentioned earlier, 3d printing as a means to reduce costs is a popular idea in the academic literature on upper limb prosthetics. However, the claims are sometimes based on material costs alone, and costs are rarely compared with the production costs of alternative approaches. In addition, there are a number of practical issues which make the deployment of 3d printing as a routine manufacturing method in Uganda difficult. 3d printing objects of 'residual limb-scale' dimensions can take several hours, and continuous mains power for extended periods is not guaranteed in Uganda. Printers are vulnerable to dust and humidity and require periodic maintenance, access to which can be difficult, due to the shortage of biomedical engineers. Finally, purchasing the materials required for the printers introduces more complexity into the supply chain.

The reality is that almost all sockets in Uganda are fabricated using traditional methods. Previous chapters have focused on the supply chain issues, particularly the delays associated with acquiring the ubiquitous consumables needed for socket manufacture, such as polypropylene and plaster of Paris. Below, we outline the steps involved in making a socket for a patient, highlighting the time-consuming and material resource-heavy nature of the process. These steps are taken from (Olsen et al., 2021), with additional input from Jackson Muringi (FPRRH).

(1) *Patient History*: Background information is discussed, and sensitive and painful areas of the limb identified. It is noted that most patients have very high expectations of their prosthetic limb and hence time is taken to discuss the potential limitations and functionality of the prosthesis on offer. Although this is usually time consuming, experience suggests this is an important step in supporting acceptance of a prosthesis.
(2) *Limb preparation*: Areas of interest are marked on the limb or sock using an indelible pencil e.g., the bony prominences, and any sensitive areas.

(3) *Limb shape capture*: The limb is wrapped in plaster-soaked bandages, whilst the prosthetist moulds the plaster and applies pressure over areas that may accommodate a tighter fit, to aid socket suspension. The cast is dried and then filled with plaster to create a positive model of the limb. A metal pipe is inserted into the middle of the positive mould (before it sets) for alignment reference and later attachment.
(4) *Initial modification*: The positive model is adjusted and smoothed by the prosthetist. In well-resourced settings, a diagnostic socket is made at this stage using a transparent plastic sheet vacuum formed around the model, which allow the prosthetist to check the fit before proceeding to make the definitive socket. This step is typically not performed in Ugandan workshops, due to resource limitations.
(5) *Wrist Attachment*: The wrist component is attached to the positive mould using removable nails
(6) *Socket fabrication*: The final socket is made, generally using the draping technique, as follows:

- A polypropylene rectangle is cut, based on the length and largest circumference of the positive mould
- The polypropylene rectangle is heated in the oven between 180 to 230 degrees until it softens
- The malleable polypropylene sheet is draped over the mould and the ends joined to create a seal, while suction is applied to allow the plastic to conform to the shape of the mould.

(7) *Final additions*: The socket is separated from the positive mould, final components are added, which may include the hand or any permanent screws.

Minor adjustments to the socket shape using a heat gun are possible, but major changes may necessitate a new socket.

A recent innovation that has emerged onto the market in recent years is adjustable sockets. A review of these devices can be found here (Baldock et al., 2023). A small number of these devices are available 'off-the-shelf', meaning they come in a number of standard sizes, and the clinician is only required to make simple adjustments in order to fit to the patient. Others have reported on the potentially game-changing impact that a demonstrably acceptable, lower-limb off-the-shelf socket could have on

prosthetics services in resource-limited settings (Dillingham et al., 2022; Kenia et al., 2021). In the following section, we report on a study that we carried out in partnership with the team at FPRRH to test an off-the-shelf upper limb system, the Koalaa ALX. The decision to select the Koalaa product was in part based on the potentially significant advantage their adjustable, off-the-shelf socket offers over conventional sockets (as discussed above). The selection was also guided by the fact that the product already had been tested in one or two low resource settings, including Sierra Leone. The Koalaa offered a range of easily interchangeable simple hands that offered acceptable cosmesis and some prehensile function, which aligned to a reasonable degree with the feedback we received in our co-design workshops. Finally, the cost of these devices is somewhat realistic for the Ugandan market. Later in this chapter we revisit this issue.

Evaluation of the Koalaa ALX System

The study, funded by the UK Medical Research Council, took place in 2023/24. The full study protocol and results are published elsewhere (Pickard et al., in review). In this chapter, we will briefly summarise the methods, and then discuss selected findings in detail to illustrate the potential value of our methods as a means to quickly and effectively gather objective data on the levels of actual prosthesis use and the impact that use of a prosthesis might have on physical behaviours, personal wellbeing, autonomy and productivity.

The Upper Limb Study

The Upper Limb study explored the feasibility of introducing appropriate adjustable sockets and prosthetic hands, a low-cost patient support system and a local repair toolkit. Figure 7.2 shows the Koalaa ALX , an adjustable, off-the-shelf, prosthetic system for people with limb absence below the elbow. This easily fitted device has been used in the UK, and in a small number of low-resource settings. The socket comes in a range of 4 standard sizes (S, M, L, XL). The person fitting the prosthesis takes a small number of measurements of the limb, selects the appropriately sized socket, then cuts the socket to length. Finally, an end cap which connects to a 'dock', is fitted to the distal end of the socket. This allows the user to quickly attach the hand or functional end effector of their choice to

the socket. It also allows the user to rotate the hand about the long axis of the socket. Once the user has donned the socket, they can adjust the fit via a Velcro strapped cover.

As mentioned earlier, there is an almost complete absence of studies of upper limb prosthetics in Uganda, or indeed most Sub-Saharan African

Fig. 7.2 A user wearing a Koalaa ALX adjustable socket and cosmetic hand. Next to the Koalaa is an example of one of the grippers which can be interchanged with the cosmetic hand (Koalaa Amy gripper)

countries. A review of methods for the evaluation of upper limb prosthetics can be found here (Kenney et al., 2021). There are challenges with delivering studies using certain of the 'standard' methods in a Ugandan context. For example, there are no dedicated movement analysis laboratories, and many of the clinical outcome measures have been developed and validated for use in high resource settings. Therefore, alternative outcome measures, which were appropriate for the context and could be delivered efficiently were required.

In our Fit4Purpose study, we interviewed 17 people in Uganda, who live with upper limb absence. found that there was a stigma associated with the condition, coupled with a desire (by some) to hide their disability or "look normal" (Morgado Ramirez et al., 2022). The majority of participants had never had access to a prosthesis. We found interviewees reported avoiding some social or other situations. The reasons for this included a lack of confidence in performing tasks without the help of family, as well as comments from others who observe their limb loss. Access to employment was a common and major problem.

To capture the impact of providing users with an upper limb prosthesis we collected data on whether people chose to wear their prostheses in their daily lives, and the extent to which people participate in activities outside of their homes. Specifically, the aims were to:

1. Set up a pilot service to deliver the Koalaa system. The service included training for technicians, and a support package for users including access to a 'limb buddy' and a simple repair toolkit.
2. Test the feasibility of delivering the training and support package.
3. Collect pilot data on the impact of the package on real-world use of prostheses, and patient patterns of activity inside and outside of their home.

Participants met the following criteria: unilateral upper limb absence at the trans-radial level, aged 18 years or older and owned a phone, or were willing to learn how to use one.

In the first phase of the study, we interviewed ten orthopaedic technicians from workshops across Uganda, to understand the issues hampering their ability to deliver upper limb prosthetic services, with a particular focus on repairs. We also set up a pilot service to deliver the Koalaa prosthesis at FPRRH. The support package included a minor repairs kit for

participants and access to a 'limb buddy'. The 'limb buddy' term refers to peer-peer support for new users; and was pioneered by Koalaa in the UK. Following fitting of each of the two limb buddies with a Koalaa ALX system, and training on their role as limb buddies, phase two commenced.

Following informed consent, we recruited 8 people with upper limb absence. To identify how the provision of the prosthesis and support/maintenance package impacts on the users we captured their real-world behaviours over a period of a minimum of 7 days using a thigh worn ActivPal device before fitting (T0), immediately post-fitting (T1) and at 6 months (T2). The resulting data could be used to characterise periods as either at home or outdoors. We also recorded prosthesis wear periods from a prosthesis worn Axivity activity monitor. Participants were interviewed at T2 to capture their experiences of participating in the study, including their views on the Koalaa system. The protocol and full results are described in detail in our paper (Pickard et al., 2025, in review), so here we focus only on the activity monitoring and interview data, with a view to illustrating their potential value, particularly when combined.

Activity Monitors

Two types of monitoring devices were used in this study: (i) a thigh-worn ActivPal device, and (ii) a prosthetic wrist-worn Axivity device. Data from the Axivity sensor was analysed to extract periods of prosthesis wear (Chadwell et al., 2018); Data from the ActivPal was analysed to record the number of steps, and classify periods into 'home' or 'community' (Speirs et al., 2021). The data from the two monitors were downloaded after each monitoring period and time synchronised to allow for the analysis of the person's behaviours while wearing and while not wearing their prosthesis. Data were stored locally on the monitors and downloaded by a member of the research team onto a password protected university laptop.

The ActivPal monitor data were analysed as follows. This ActivPal software was used to group the data into 60s 'epochs' (time windows), with each 60-second epoch broken down into a summary number of seconds according to each of the activity classifications. The resulting CSV file contained a breakdown of activity classifications and the number of steps determined by the algorithm for each 60 second epoch throughout the entire data collection period. The classifications were sedentary (sitting), upright (standing), cycling, primary lying, secondary lying, seated transport, and non-wear. Primary lying time is the longest period spent lying

down over the course of one day, and secondary lying time represents any other times spent lying down for at least 60 minutes. Each 60-second epoch was labelled according to the dominant activity within that period. So, for each 60 second epoch we had the classification of activity, and whether or not the prosthesis was worn in that period.

To visualise the data, our team has produced a method for plotting synchronous data from the ActivPal and wear periods, derived from the Axivity monitors. Previous work by Granat (Loudon & Granat, 2015) and subsequently, Chadwell (Chadwell et al., 2018), demonstrated how Archimedes Spirals could be used to visualise time series activity data over an extended period of time.

We plotted minute by minute data from both monitors, as shown in the example in Fig. 7.3. As can be seen, the data recording in this instance started around 4 p.m. on the Thursday and continued to around 4 p.m. the following Thursday. The colours indicate the minute-by-minute activity classification extracted from data collected using the ActivPal thigh-worn monitor. The black bands around parts of the spiral indicate periods during which the prosthesis-worn monitor data showed the prosthesis was being worn. In cases where there was no ActviPal data (e.g. after around 2:30 p.m. on the final Thursday), the black banding changes to fully black shading. The figure in red is the average number of steps per day taken over the recording period, while the figure in blue is the average length of time (in hours/day) the prosthesis was worn over the recording period. As can be seen, this participant wore their prosthesis for most of the day, every day, typically from shortly after they woke up (around 8:30 a.m.) to shortly before they went to sleep (between about 8:00 and 9:30 p.m.). During the day we can see numerous short bursts of walking (in red), interspersed with sedentary periods, periods spent on transport and lying periods.

Upper Limb Case Studies

Here we report on two case studies, pseudonyms Charlotte and Maggie. The interviews are cross-referenced, where appropriate to the spiral plots of activity monitoring data.

Charlotte is a 25 year old woman who lost her hand in a domestic violence incidence at the age of 23 and is a first time user. She is an unemployed single parent with 2 children and lives with her parents who help her with her children. Following an argument with her partner

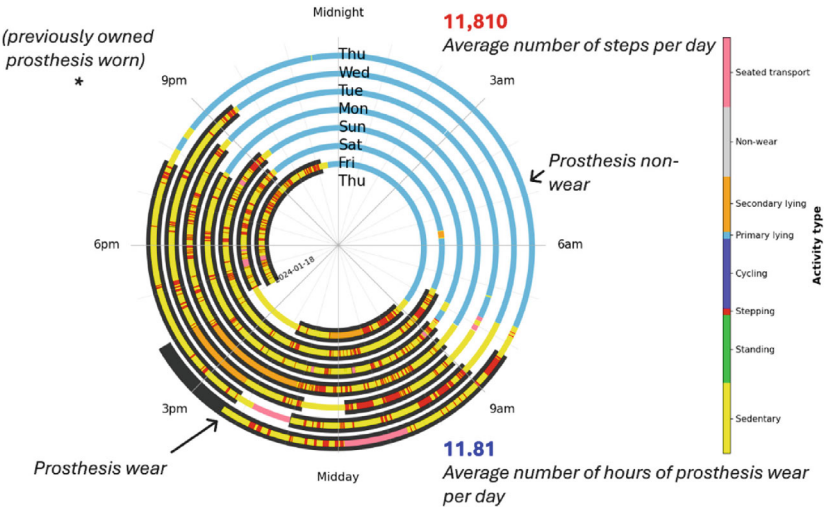

Fig. 7.3 Example of spiral plots showing synchronous prosthesis wear/non-wear, and physical behaviours (Each loop of the spiral represents 24 hours, with midnight at the top and midday at the bottom. Colours within the spirals represent the activity classification. Periods of prosthesis wear are indicated by black banding along the edge of the spiral. Where activPAL data were unavailable, prosthesis wear periods are still shown without the overlaid activPAL data). In cases where a star symbol is shown to the top left of the spiral, this indicates the presented wear data is collected during wear of the participant's own prosthesis, rather than the Koalaa ALX. The figure in red represents the average number of steps per day over the recording period, and the figure in blue represents the average number of hours/day the prosthesis was worn over the recording period

he attacked her with a machete Chapter 2 discusses the issues of interpersonal and intimate partner violence, and the indications that it may play a particularly prominent role in upper limb loss. Given the severity of the injury, she was taken to the National Referral Hospital for amputation and later advised that she could access a prosthetic limb in the workshop there but at a cost of 3 m Ugandan shillings, which was unaffordable. On return home she struggled with basic living chores such as cooking and washing. She was also concerned at her appearance stating that people 'looked at her like a disabled person'. She heard about the possibility of accessing a Koalaa limb from a friend.

Prior to getting the device Charlotte says, '*I did not feel sad because I did not know that it was there. I did not know that I could get a hand*'. This is a common experience in Ugandan context where the level of awareness of upper limb devices is so poor—see also the discussion in Chapter 6. At this point Charlotte describes how she would cover her limb with a shawl when she went out in public.

We can see from Fig. 7.4 that during the daytime of the recording period prior to her receiving her Koalaa (T0), the data shows short bouts of walking, interspersed with longer sedentary periods. On average, her step count was just over 9000/day.

She describes how, where she first received the Koalaa device she was afraid of using it and people seeing it as her family and the wider public had not been exposed to this type of technology. We can see from Fig. 7.5 that she did wear the prosthesis on occasions, for short periods, over the first few days, and showed two longer periods of wear towards the end

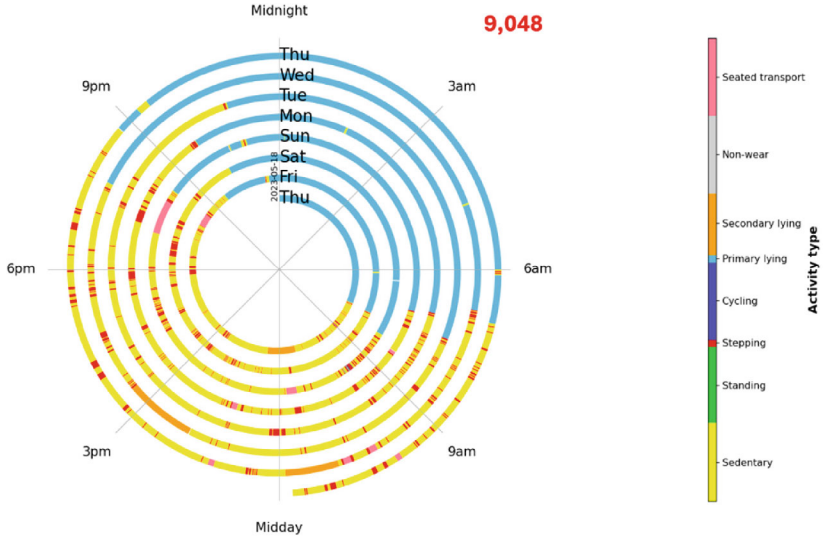

Fig. 7.4 Activity monitoring data (T0) for Charlotte[6]

[6] Note that because Charlotte did not possess a prosthesis on entering the study, the Figure only presents data from the ActivPal monitor.

of the recording period. However, her average wear/day was just over 2 hours. There was no clear indication of a change in the amount of walking/day she was carrying out in this period.

She didn't use the device much for the first 3 months until her parents encouraged her to try it out:

> *When I had just received it, I was afraid of it. I would put it on and even fear to leave the house. But eventually when [my parents] advised me, I put in on and now I am free with it.*

After a few months her outlook changed:

Now, when I put it on and walk [about in public], I do not feel any shame from people. Apart from those making fun of me [in a joking manner], but personally, I do not have any problem with the device. I no longer feel afraid that people will see me and get scared. Figure 7.6 shows a dramatically increased pattern of prosthesis wear, with wear evident on

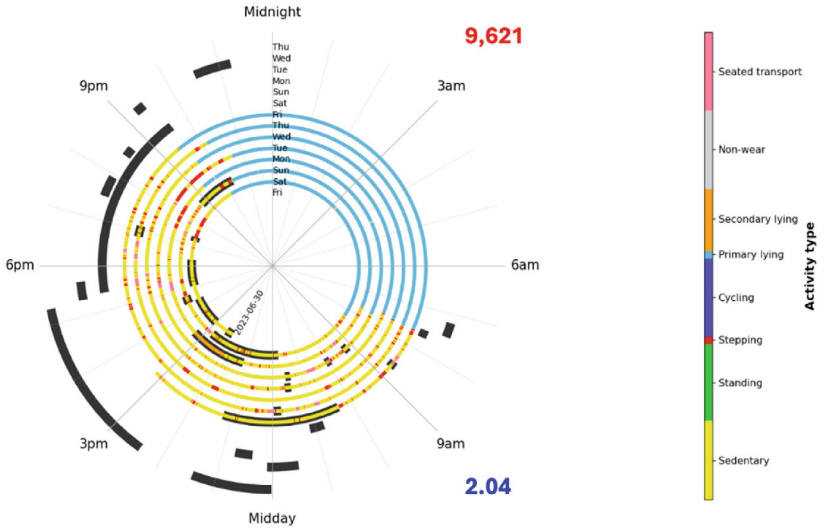

Fig. 7.5 Activity monitoring data (T1) for Charlotte[7]

[7] Note that we have a longer recording for the prosthesis worn Axivity monitor (~13 days), than for the Activ Pal monitor (~7 days).

every day over the recording period (~6 months after first fitting). Particularly consistent wear was seen in the morning and early afternoon of most days.

Her decision to start using it was based both on people getting used to seeing it but also the fact that she realised its functional value. Later in the interview we see that her behaviour is more nuanced, and, unlike most other participants, she has greater concern about the cosmetic hand than the attachments. She describes how she assesses the social situation when deciding whether to wear the cosmetic hand or not. She wears it for professional activities and also for the more routine social events such as going to church (where she perhaps knows people better) but is reluctant to wear it at larger social occasions (such as funerals which attract several hundred mourners in the Ugandan context):

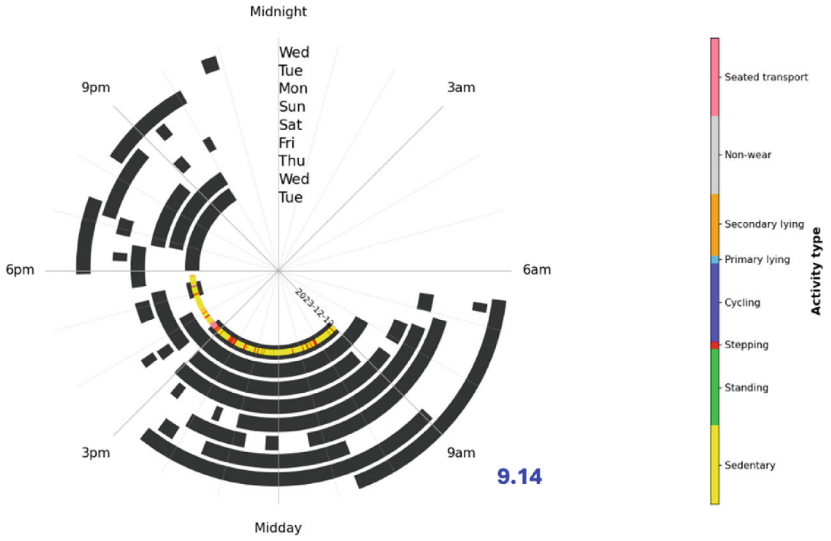

Fig. 7.6 Activity monitoring data (T2) for Charlotte[8]

[8] Unfortunately, the ActivPal monitor only recorded data for the first few hours of this recording period, so we are unable to provide a reliable estimate of steps/day. However, the average wear/day figure is presented.

It depends on where I was going and the people I was going to meet there. I go with it to church or the market because I am a trader, so I go with my device. You think about the fact that there will be very many people, and they will stare at you and make you feel ashamed. For example, when there was a burial, I wouldn't wear it because there are usually many people, and they ask a lot of questions.

Charlotte feels embarrassed when people tease her at such events: *When they come and touch my hand and find out it is not an actual hand, they say some un nice stuff.*

It is interesting to see how Charlotte finds the terminal devices less embarrassing than the cosmetic hand:

When I am wearing the [Rushton ALX], I am not ashamed. But if I put on the cosmetic hand, I feel that it causes me some difficulty.
Q: So, they do not tease you when you are wearing the terminal device?
No, they do not. Maybe because the other one looks like an actual hand, but when someone touches it, [they realise] that it is not a hand. But this one [Amy ALX], they even notice it from a far that I am not wearing the one that looks like a hand.

It seems that the cosmetic hand, masquerading as a real hand, stimulates more interest and teasing than a device that is clearly artificial. There is a well-known phenomenon known as 'uncanny valley' (Mori, 2012) which describes the perception of eeriness associated with artificial objects that are close to, but don't quite look like, the human body part being mimicked. A good discussion of the issues around prosthetic hands can be found here (Poliakoff et al., 2013), and it is possible that some of the responses she experienced were associated with this.

Charlotte describes using the hand for more functional than cosmetic purposes including lifting and carrying items during her work at for tasks at home. This includes carrying quite heavy objects:

When I am going to start my day, I quickly remember my device and put it on. I start carrying the things (up to 5kg in weight) to my stall, [and leave it on] till nighttime. It helps me carry a bucket or some luggage. I put a broom in (the Amy ALX) and I start sweeping.

The second case study is Maggie, a 24 year old student who suffered catastrophic damage to both an arm and a leg as a result of a burn injury

as a young baby. She was fitted with an upper limb device in Fort Portal 7 years previously. Figure 7.7 shows data collected at baseline (T0) for Maggie. We can see that she wore her original prosthesis extensively on some days. Indeed, on the first day of recording (Wednesday) she wore her prosthesis from the evening through to early afternoon the following day, and on the last day of recording, she wore her prosthesis for over 24 hours, almost continuously. The ActivPal data suggests she was lying down for significant part of these periods, which is somewhat surprising. Average prosthesis wear time over the recording period was over 9 hours.

Figure 7.8 shows monitoring data collected in the period immediately following Maggie being fitted with her Koalaa ALX. In contrast to the patterns of wear seen when using her original prosthesis (Fig. 7.6), we see more regular patterns of wear of the Koalaa, particularly in the mornings, and we don't see any of the prolonged (overnight) periods of wear.

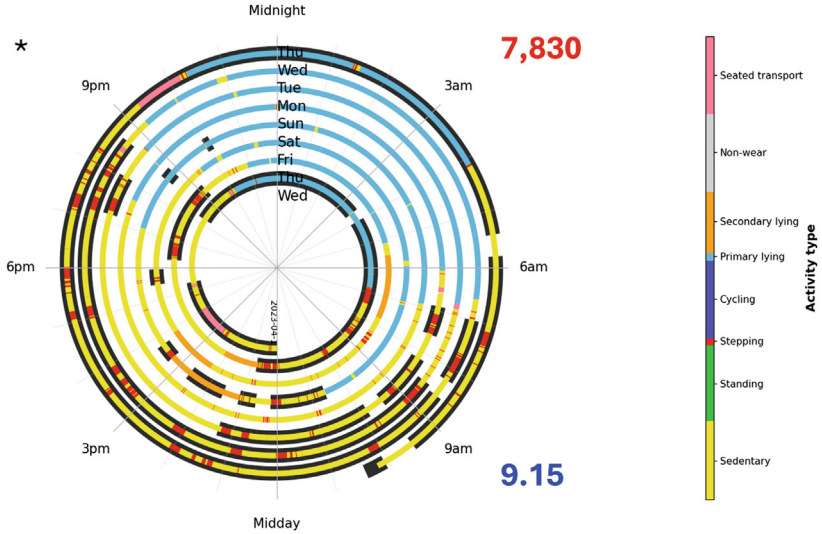

Fig. 7.7 Activity monitoring data (T0) for Maggie (own prosthesis)[9]

[9] In contrast to the data collected at T0 for Charlotte, Maggie entered our study with her own prosthesis and hence we were able to record both prosthesis wear and physical activity.

Average wear time and average step count/day were both slightly lower than those seen when monitoring Maggie at baseline, likely influenced by the absence of any overnight wear.

Six months later (T2), we can see that Maggie's data shows an increase in both average wear time and number of steps/day (Fig. 7.9). Again, the pattern of wear is skewed towards mornings and early afternoons. We also see some use late at night emerging (Saturday and Sunday) perhaps when she goes out with friends socially.

In her interview, Maggie explains how the Koalaa has a much improved cosmetic appearance to her previous hand referring specifically to the colour match:

> *The first one I had; the appearance was not good. People could look at me like I was like a tourist attraction saying this colour is brown, and the other is black. My skin colour was not matching. I (now) feel comfortable when I am in public, people take time to recognize it is an artificial hand.*

She also explains how the smaller size of the Koalaa enables her to wear a wider range of clothes:

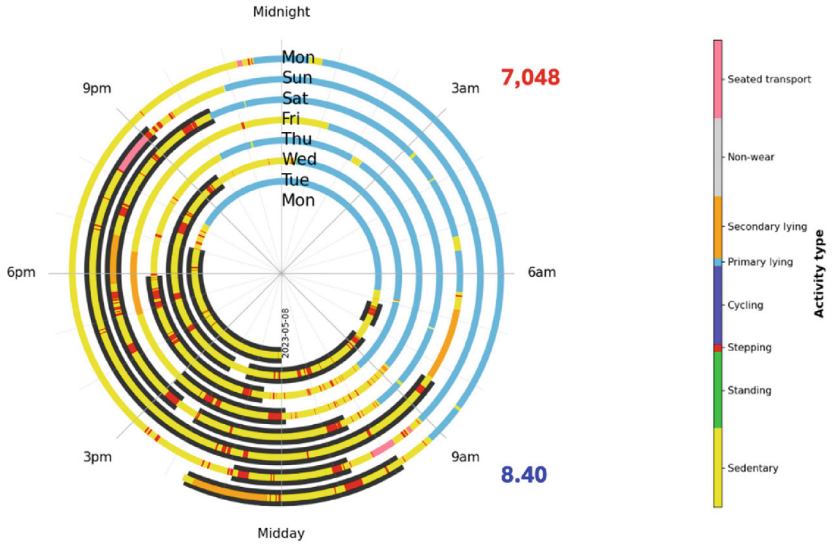

Fig. 7.8 Activity monitoring data (T1) for Maggie

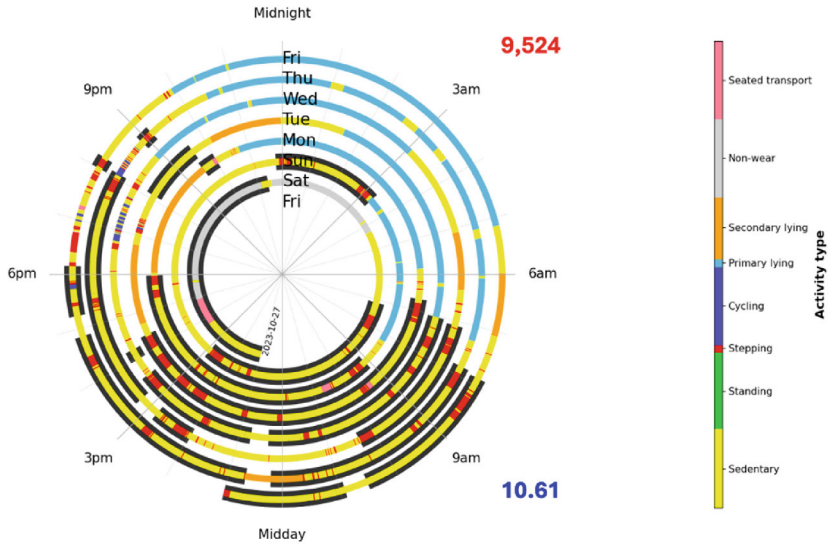

Fig. 7.9 Activity monitoring data for Maggie (T2)

> *The other one was a bit bigger, and I could not put on long sleeved shirts which are fitting, and I feel comfortable. The other one used to over show the hand joint, so I had to put large things to hide it.*

It is interesting to contrast this with Charlotte's experience. Charlotte is doubtless comparing her Koala hand with her real hand whereas Maggie, having no memory of life with a real hand makes a rather different comparison with her pre-existing prosthesis.

Maggie is a sportswoman and throws the javelin. She describes how having the Koalaa helps her in this activity:

> *[The Koalaa] rotates, the other one was staying in one side. This one I can turn the device to looks behind or in front. Whenever I go for javelin, I remove the cosmetic hand and put another part, which is for holding the things [Rushton ALX]. Those are the things which encouraged me to love it.*

On the other hand, she describes not using the device when at home. Perhaps, once again, she has grown used to using her stump over her entire lifetime for such tasks:

Wherever I'm outside I'm always putting it on (including classes at University). There's no way it can support me when I'm cleaning the house because I am not comfortable. I feel free when I am doing my work with my own half hand, reason being I started using these devices recently, I am not yet used to them.

In addition to wearing it in class and for sports Maggie describes the importance of using it in social contexts and managing the stigma she experiences even amongst friends:

When I am wearing it, I feel comfortable with people and also, they feel comfortable with me. The other one I had, when I used to walk with some of my friends, they would act like they are not with me. When they meet their 'big' friends, they would be like, 'This girl's hand', you can see it in their reaction, they are not comfortable with me. And wherever I am putting on this hand, they are comfortable with me. When I am not putting it on, they will be asking me, where is your hand, you could have put on your hand, which shows that they are happy when they are seeing me when I am full with my hand, rather than moving without a hand. And whereby when I got this one, they are happy with it, they were like, 'the other one, you leave it'. Up to now I stopped using it. I am comfortable with this one, wherever I'm going outside or parties, I always with this one.
[I now go out more] because I used not to move around, but these days I can go to see people swimming, I can go and visit my friends in their homes, in the hostel where I am staying at campus. I go to their home place like hostels, I talk to them, and they are free with me. Whenever I am walking on the way, people do not over look at me. They do not turn very fast to look at my hand as it is matching with my colour. Yeah, it is not stressing me at all, and I can move long distances without feeling tired, unlike the first hand which was very heavy for me.

Maggie is now so attached to her new hand and concerned that it may become damaged that she sometimes tries not to wear it too much. This was a particular concern with her previous prosthesis which had a glove covering:

I was protecting too much the glove because they told me once I tear a small part, it will get broken. I never used to over put it on. I could use it when I am going to big functions.

This concern about 'over-wearing' and potentially damaging the hand limited her use of the Koalaa at first:

> *At first, I never used to put it on. When you gave it to me, it was something big to protect so that it does not get spoiled. I was overusing it when I was going to my friends, campus, but when I had gone for holidays, I kept it [stopped using it] until I came back to campus. Because at campus, I have to look nice so that people can be near to me. Some people feel uncomfortable when they sit next to you when you are not fully. But when I am putting on my hand, someone feels comfortable and comes and sits and talks. Even me, I feel comfortable when I am fully. That forced me to keep it safe so that it doesn't get spoiled.*

Similar reports of changes to behaviour to avoid damage to the user's prosthetic hand have been published elsewhere. For instance, in a study in the Netherlands and Austria, one participant "[…] *but I am way too scared that something goes wrong: BAM, 2000 euros … or the glove gets damaged, BAM, 300 euros. Then I think … well, I rather won't try it then. […] It's just too expensive. And if you had it damaged a couple of times and then you can't use your prosthesis for two or three weeks…*" (Franzke et al., 2019).

The only factor Maggie described as impacting her use of the Koalaa was the weather as it becomes quite hot:

> *When I am putting it on, I put on long-sleeved clothes and when there is too much sunshine, it is too hard to put them on from morning to evening. Sometimes I am forced to put on short-sleeved things so that I move freely in the compound when there is not too much heat. But it would be better if I there is a way, I can reduce the heat. You know, this hand is a carpet (referring to the covering). When I apply a sweater there is too much heat which is disturbing me inside.*
>
> She still maintains that the Koalaa is an improvement on her previous device:
>
> *The other one was too much. I could put it on knowing I am going to use it for 6 hours or 8 hours and remove it. This one, at least the carpet has that soft part inside so I can stay with it.*

The issue of heat also contributes to sweating which causes sockets to develop and smell. This was a concern for many users:

> *The first one used to get a bad smell much faster than this one. This one the smell was not too much.*

The issue of sweating and smell in prosthetic sockets is little discussed but was raised by a number of our interviewees. A study exploring the impact of thermal discomfort and associated issues in lower limb prosthesis users found that a foul smelling socket, unsurprisingly impacted on social confidence (Williams, 2020). There is potential to improve the thermal properties of the Koalaa and further work to address this is recommended. Finally, on a related note, we are exploring the potential to locally manufacture the socket covers. Given most orthopaedic workshops have access to both potentially suitable materials (e.g. leather) and sewing machines, the socket covers should be relatively straightforward to manufacture. Koalaa have responded positively to this suggestion, which is encouraging further work in this area. Being able to easily and quickly replace a cover that either becomes smelly or degrades mechanically, would represent a useful step forward.

Discussion

Even in high resource settings, there is limited evidence on the effectiveness and acceptability of (particularly upper limb) prosthetic devices. Much of the literature reports on early stage studies of novel technologies, with few high quality clinical studies of commercially available devices. There are even fewer cost-effectiveness studies, arguably a particularly critical problem in low resource settings, such as Uganda (Kannenberg & Seidinger, 2021).

New technologies, such as the Koalaa, present clinicians and service providers with a choice—whether or not to stick with existing technologies, with the well-understood limitations and such decisions are very difficult in the absence of evidence (in context). Trials of new prosthetic devices are expensive, and traditional study designs capturing, for example, impacts on users through validated questionnaires, or structured measures of function (such as Southampton Hand Assessment Procedure (Light et al., 2002), are difficult to implement in a Ugandan setting. As

argued above, many of these outcome measures may not be directly applicable in a Ugandan setting, and outcome measure validation studies in such settings would add to the cost and delays.

The combination of interview data with real world data on whether participants choose to wear their prosthesis, concurrent with physical behaviour activity gives a very detailed insight into the value of a prosthesis to users. In contrast to, for example, some clinical outcome measures, it is context agnostic, so could be deployed in any setting without the need for separate validation studies. As described in our paper on the study (Pickard et al., 2025, in review), an additional metric that can be derived from the thigh-worn Activ Pal monitor is periods spent at home or in the community. So, the combination of data on wear periods, with an estimation of when people spent time out in the community provides a valuable dataset, particularly when considering the impact of any prosthetic intervention on the economy. Of key importance, such approaches are very quick to implement.

It would be interesting to explore how some of the devices we have seen being handed out via outreach camps, are used (or perhaps not), and to gather the perspectives of the recipients as to why they chose to wear or not their prostheses. In Chapter 4, an interview with Miriam found that she had been given 10 legs at various times, and at least one of which she abandoned after just 2 days of use. Closing the loop via activity monitoring, might help to support a more rational approach to prosthetics provision.

Earlier in the book we note that orthopaedic technologists' practices in socket manufacture appeared to be based on historical practice, rather than the merits of different approaches. Our 2020 review of activity monitoring in prosthetics (Chadwell et al., 2020) identified that the approaches were not yet suitable for regular clinical deployment, but as the technology advances (tools to extract more/better information from the sensors are constantly emerging), this situation will change. When it does, this could open up opportunities at a clinical centre level, to test any new components they are offered, hence potentially giving a greater degree of autonomy over prescription decisions and acceptance (or otherwise) of donated components.

Future work should consider the additional value of using the data from activity monitoring as prompts during interviews. For instance, in our study it would have been very interesting to have explored in more depth some of the findings revealed by the monitoring data. A good

example is the finding that Maggie wore her original prosthesis overnight on more than one occasion, but we didn't see this pattern of behaviour when she wore her Koalaa. In our study, the activity monitoring results had not been processed by the time the interviews took place.

Priority 9 in the WHO's Rehabilitation 2030 Call for Action is 'Building research capacity and expanding the availability of robust evidence'. The aim of universal health coverage for amputees in the context of the massive existing gap in provision in Uganda demands quick and cost effective solutions. Services are under growing pressures and hence technologies that can improve the efficiency of services, while offering patients prostheses that are demonstrably acceptable to patients are to be welcomed. Our findings, reported in detail elsewhere (Pickard et al., in review), suggest the Koalaa ALX system is feasible to deploy, without the need for the complex set of materials and machinery needed when making traditional sockets, and is acceptable to patients. K4C is currently working with Koalaa to reduce the unit price of a basic Koalaa device to around £500 to test the potential for entry into the Ugandan market.

CHAPTER 8

Conclusions and Policy Recommendations

Abstract This chapter reflects on the findings presented in the previous chapters on the state of rehabilitation services in Uganda, the impact of the intervention and the potential role that this has for the development of Universal Health Coverage for people impacted by major limb loss. It begins with a discussion of the relationship between health systems and national economies as the ultimate source of sustainability. And, in the context, on the role of overseas development assistance. The Chapter then aligns our key findings with the key challenges identified in the first Ugandan National Rehabilitation and Assistive Technology Strategic Plan.

Keywords Evidence-based policy · Universal Health Coverage · Economic development

Economic Development and Health System Sustainability

Ultimately, the efficacy and sustainability of all health systems is inextricably linked to the strength and functioning of national economies. Economic development transfuses health systems (Pazirandeh, 2011). Equally, health systems create huge opportunities for economic development. They should not be characterised, as is often the case, simply

L. Ackers et al., *Delivering Universal Health Care to People with Major Limb Loss or Damage in Low and Middle Income Countries*,
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as a drain on resource. Odedo et al. (2021) citing a Lancet Commission Report (Jamison et al., 2013) deploy the concept of 'full income approaches' to capture the multiplier effects of health investment that extend beyond individual productivity to wider benefits. Better health they contend, improves labour productivity, education, attracts foreign investment and increases worker-to-dependent ratios.

Chapters 2 and 3 have demonstrated the huge potential for income generation in rehabilitation markets. Much of this at present operates within the shadows of the formal economy supporting the personal income of moonlighting health professionals. Understanding the relationship between economies and health systems is pivotal to the delivery of Universal Health Coverage (WHO, 2019). Savage et al. highlight the essential, if neglected, relationships between ODA efficacy and markets arguing that, 'Development outcomes are inextricably linked to the health of the marketplace that delivers products and services to people in LMICs' (2021: S124). Why then does global health and the actors involved in it ignore the potential for, and their responsibilities to engage in 'market shaping'?

The World Health Organisation's Analysis of the Health Market in Uganda (WHO, 2023c) simultaneously acknowledges the importance of strategic investments in Human Resources for Health for the attainment of Universal Health Coverage but also the contribution that the Health Sector makes to economic development (WHO, 2023: XI). Whilst many papers recognise the impact of limb loss on individual productivity, less attention has been paid to the impact that assistive technologies-focused health systems have on the efficacy of markets and, ultimately, the potential for device fabrication. Emerging interest in this neglected field inherits the tendency in global health to characterise health systems in LMICs as dysfunctional, under-funded and 'broken'. The (implicit) role of foreign intervention, as we have seen, is to patch-up, top-up and mend. Humble (citing Sachs, 1992) refers to the 'emotionally charged narrative of development' as a 'myth which comforts societies, and a fantasy which unleashes passions' (Humble, 2012; Rahnema & Sachs, 1992). Nowhere is this articulation of the desire to 'help' or 'donate' seen more clearly than in the support for people with limb loss. Harkins et al. describe what they call the 'relief' approach to P&O service provision in LMICs suggesting that whilst, 'it is tempting to follow a route of instant gratification, without the planning and implementation of sustainable programmes, the initial achievements are nullified' (2013: 357). King

and Koski echo these concerns in their thought piece, 'Defining global health as public health somewhere else'. They urge those engaging in global health, often motivated by the altruistic desire to 'do something' to reflect, 'why practise somewhere else?' This question, they argue, is not designed to discourage overseas engagement but rather to avoid 'clumsy attempts to help on our terms that do more harm than good' (2019: 3). They suggest that this assumption, that we can do good in health systems other than our own, is often predicated on an implicit belief in an 'expertise gradient' arising simply by virtue of 'coming from somewhere else'. This is compounded by an assumption that so long as the intervention is to help 'global health interventions need not be vetted' by target recipients. This lack of accountability often manifests itself in ignorance of the long-term impacts and sustainability of interventions—especially short-term interventions—and the negative unintended consequences of these. The donor interventions we have reported on in this study exemplify the approach critiqued by King and Koski and the negative impacts of this on health and economic systems.

Holloway et al.'s review of innovation strategies to improve access to assistive technologies in LMICs attributes health systems inertia and policy resistance to sheer complexity (Holloway et al., 2021). Our experience of working in Uganda for the past 15 years and trying to make sense of what often appear to be irrational decisions (or more often, non-decisions) has led us to reverse the lens and view the health system from the premise that, far from being broken and stifled by poor leadership, it delivers exceptionally well for many stakeholders. This includes not only politicians, policy makers and donors but also some health workers. As Chabal et al. (1999) poignantly put it, 'Africa Works' at least for those able to leverage some power. A combination of strategically articulated donor-dependency with endemic corruption has enabled health systems to entrench inequalities extending the chasm that exists between the 'haves' and the 'have-nots'—and able bodied and those with disabilities—in an increasingly polarised society. Moyo (2009) describes the 'malignancy' of Aid both in terms of dependency-generation but also the suffocation of national economies. Overseas Development Assistance (and 'Aid' in general) have inevitably skewed policy making in LMICs encouraging alignment to internationally designated global health priorities and the funding streams and opportunities for personal gain associated with them. The impact of this on prosthetic services is profound. This reflects the historical dominance of 'humanitarian' approaches where limb loss

is linked to conflict. Here ODA has a very specific spatial and temporal quality with large injections of funding impacting specific geographies and often specific groups for short periods of time (Global Partnerships for Assistive Technology, 2021; Pazirandeh, 2011). Okello et al. describe the mobilisation of Aid (and NGO infrastructure) in Northern Uganda as designed to meet 'the immediate needs of victims'. As overseas funding is withdrawn in the transition to peace, they suggest that the government failed to invest in maintaining those services, contributing to a state of chronic dependency. The 'emergency' context overrides concerns about service integration, capacity-building and fiscal sustainability. Precisely those concerns highlighted in the WHO's Call to Action and Uganda's response to that through the National Rehabilitation and Assistive Technology Strategic Plan 2024/5–2029/30 (Uganda Ministry of Health, 2024).

A specific manifestation of this 'humanitarian legacy' is the tendency to focus on the donation of whole devices (prosthetic limbs) or 'kits'. The rationale for this 'whole limb donation' approach reflects the emergency context, the perceived lack of *proximate* health worker expertise and the demand from donors for simplistic 'measurable' audit mechanisms (number of legs distributed). Unfortunately, in the transition from conflict to a context where road traffic accidents, inter-personal violence and diabetes form the major cause of limb loss and damage, this legacy and the architecture associated with it thrives.

Achieving systems change is complex; paradigm shifts are rare and often 'boomerang'. The approach to change promoted in the Complex Intervention described in this book is one based on:

1. Genuine and active respectful partnership with all key stakeholders (including multi professional perspectives and users)
2. Continued reflection on the dynamics of whole systems (political, economic and social welfare)
3. Within that frame, attention to the detail of specific interventions to foster evidence-based progressive incrementalism with iterative reflection on potential externality effects.

The intervention has led to the upgrading of the FPRRH workshop such that it is now the only public workshop in Uganda sustainably providing prosthetic services, free at the point of use. We have moved

away from 'donations' with the exception of the second-hand componentry. Although STAND is the only organisation we have experienced in the East African context, Somerville and Nagy (2024) report on other partnerships involved in the refurbishment and redistribution of disability equipment from the UK to LMICs (specifically Romania[1]). The authors celebrate the role that this form of 'recycling' can play in the reduction of waste in HICs and the associated environmental impact[2] of waste disposal whilst augmenting device supplies in under-resourced LMIC settings. Their empirical work very much supports our own experience that, 'the development of strong, honest, transparent and continued relationships between organisations' underpins the success of partnerships (2024: 1).

It is interesting to witness the progressive increase in cases and the greater distances patients are travelling to access these services, often bypassing other workshops including the National Referral Hospital. Steps have been taken to identify materials and begin to predict demand over a 3-month lead time. This has resulted in larger volume orders being sent by sea to Uganda and a corresponding reduction in unit costs. The next steps are to assess the possibilities for extending this approach to other public facilities whilst at the same time building partnerships with PNF and PFP consumers. If successful, the consolidation in demand and greater inter-sectoral coordination could significantly increase orders and reduce both prices and delays. Joint working would also consolidate advocacy potential and enable this work to be captured within the National Strategic Planning Process. The evidence demonstrates the ability to negotiate complex constraints and deploy a social enterprise mechanism to achieve the genesis of an effective supply chain for generic and ubiquitous consumables. As with all complex interventions, context is everything, and the model works in that context. The model can't be cut-and-pasted into another context and expected to work in exactly the same way. But lessons can be learnt, and interventions translated to fit other contexts. Alternative approaches may be used to support social enterprise, for example. Bouchard et al. shared respondents' ideas for alternative funding models including a levy on fuel and vehicles or harnessing 'profits

[1] Romania is listed by the World bank as an LMIC, https://www.guttmacher.org/regional-and-subregional-country-classifications.

[2] They cite one respondent who estimates that. Over a 10 year period, they have recycled around 700 metric tonnes of equipment, 'most of which would have ended up in UK landfill' (p. 4).

from private surgeries in the private wings of government hospitals to raise funds for public care' (2012: 9). The latter approach would seem more workable given the existence of private, income-generating, wings in all Regional Referral Hospitals.

The evidence generated as part of this work provides the basis for more proactive and serious negotiations with the UMoH over its policies in relation to the allocation of funding to support the National Rehabilitation Strategic Plan and its wider international commitments. Harkins et al. draw attention to the problems of existing approaches to the development of rehabilitation services in LMICS:

> Prosthetic and orthotic services have been characterised as 'good intentions, charity and small scale model programs' which will fail to meet the extensive needs of the large number of disabled persons however well intentioned. (2013: 357)

This description certainly captures the features of donor-dependent rehabilitation services in Uganda at the present time. Whilst the K4C Model could also be described as 'small scale' we hope that it creates the opportunity for policy translation and transfer based on sound principles of sustainability and social enterprise and, most importantly, integration in mainstream public services.

This final section of the book maps the findings and conclusions of our complex intervention study against the WHO Call to Action and the Draft Ugandan Strategic Plan (2023).

Policy Recommendations

In 2017 the World Health Organisation held a meeting to discuss its global commitment to improving rehabilitation services. A report on that meeting identified a number of key challenges facing services globally (WHO, 2017). These included:

- Profound **unmet need** especially in LMICs
- Projected **increasing demand** as a result of ageing and non-communicable disease.
- The requirement to address rehabilitation in order to achieve **Universal Health Coverage**.

- The importance of **integrating** rehabilitation services within an overall continuum of care.
- The necessity of **engaging users** in rehabilitation partnerships.
- The contribution of rehabilitation to wider **health, economic and social development**.

The report also identified perceived barriers to the development of rehabilitation services globally:

- Under-**prioritisation**
- Absence of rehabilitation **policies** and governance
- Dearth of **evidence** of met and unmet need
- Insufficient numbers and skills of rehabilitation **professionals**
- Absence of rehabilitation **facilities and equipment**
- Lack of **integration** into health systems

Drawing on this assessment of global need, the World Health Organisation launched its 'Rehabilitation 2030 Call for Action' (WHO, 2019). The Call for Action identifies 10 Key Areas:

1. Creating strong **leadership and political support** for rehabilitation at sub-national, national and global levels.
2. Strengthening **rehabilitation planning** and implementation at national and sub-national levels, including within emergency preparedness and response.
3. Improving **service integration** of rehabilitation into the health sector and strengthening inter-sectoral links to effectively and efficiently meet population needs.
4. Incorporating rehabilitation in **Universal Health Coverage**.
5. Building comprehensive rehabilitation **service delivery models** to progressively achieve **equitable access** to quality services, including assistive products, for all the population, including those in rural and remote areas.
6. Developing a strong **multidisciplinary rehabilitation workforce** that is suitable for country contexts and promoting rehabilitation concepts across all health workforce education.
7. Expanding **financing** for rehabilitation through appropriate mechanisms.

8. Collecting **information** to enhance health information systems including system level rehabilitation data and information on functioning utilizing the International Classification of Functioning, Disability and Health.
9. Building research capacity and expanding the availability of **robust evidence** for rehabilitation.
10. Establishing and strengthening networks and **partnerships** in rehabilitation, particularly between low-, middle- and high-income countries.

The complex intervention study reported upon in this book responds directly to the needs expressed in Key Areas 9 (robust evidence to guide planning) and 5 (service delivery models). Our goal has been to generate a deeply contextualised evidence-base, grounded in the experiences of service users and health professionals to expose the dynamics of unmet need in Uganda and generate an evidence-based model for potential replication across the Ugandan landscape. This explicitly supports the commitment to Rehabilitation Planning (Key Area 2). The Ugandan Government produced a Draft National Rehabilitation and Assistive Technology Strategic Plan (2024–2030) in December 2023.[3] The following section maps some of the key learning from our intervention onto the priorities identified in the Draft Ugandan Strategic Plan.

Integrating Rehabilitation Services with Emergency Care and Long Term Conditions

The complex intervention study reported on in this book was initially focused on rehabilitation (and prosthetic services in particular). As such, the planned work, in common with most other research in global health, took a rather myopic focus in the first instance until the experiences of users made us realise the irrelevance, to users, of professional and service boundaries. The Ugandan Strategic Plan argues that an integrated health care strategy would embrace, 'promotion, prevention, treatment

[3] National strategic planning is supported by the WHO's GRASP (Guidance for Rehabilitation Strategic Planning) program USAID, through its **Learning, Acting, and Building for Rehabilitation in Health Systems program** (ReLAB-HS) Physical Rehabilitation Programming | Inclusive Development | U.S. Agency for International Development (https://www.usaid.gov/inclusivedevelopment/disability-rights/physical-rehabilitation).

and palliative care within the broader commitment to Universal Health Coverage' (2023: 3).

Our commitment to capturing the lived experiences of amputees through life-history interviews enabled us to contextualize their rehabilitation journeys exposing the relationship between emergency and rehabilitation services more holistically. On one level this has led us to critique the merits of dissecting health systems, services and specialisms in global health research and policy. Whilst there is an emerging (but still largely implicit) recognition of the need to embrace preventive intervention in the concept of rehabilitation, emergency care remains a more discrete, highly medicalised, and often privileged domain in global health.

Ensuring universal and timely access to life-saving healthcare following unintentional and intentional life-threatening injury is perhaps the most poignant measure of health systems and health citizenship worldwide. We had not anticipated the overwhelming impact that accessing emergency care systems in Uganda had on patients. For those patients who survive life-threatening injuries (and many many more must die unnecessarily), the out-of-pocket costs of this survival have a catastrophic impact on their financial status and livelihoods. This impacts the Ugandan economy. It also destroys any trust patients, as citizens, had in the Ugandan health system and shapes future health seeking behaviour. Limb loss undermines patients' ability to recover independence and resume productive employment. This deters patients from even considering or attempting to access rehabilitation services. Key challenges in patient journeys to amputation include:

- Lack of any systematic first responder system or emergency call line
- No comprehensive public ambulance service. No paramedic training for those who do respond.
- No clear and functioning referral pathways to access emergency services
- Facilities designated to provide emergency services lack adequate equipment and supplies. Essential staff are also rarely present. This is as much as problem of grossly inadequate human resource management as it is staffing shortages. Staff are rarely present out of normal working hours and at weekends.
- The blurred boundaries distinguishing public and private sectors can be exploited by health workers to optimise personal financial gain.

- Negotiating the current referral system and frequent (extortionate) charging of patients in both public and private facilities results in extensive delays. Those that do survive face increased morbidity as a result.
- Injuries on the highway in Uganda are a major cause of mortality and morbidity. Many of the victims are motorcyclists and pedestrians. Preventive intervention is weak and undermined by endemic and normalised corruption in traffic policing.
- Many of the cases involved injuries in the course of employment but employers very rarely fulfil their legal responsibilities. The Ministry of Health has a responsibility to force employers to cover the costs of injuries and compensate employees (Uganda, 1961). Rigorous enforcement would substantially reduce the costs of public health services.
- The Ugandan Government is acutely aware of the volume of intentional injuries in Uganda occurring as a result of inter-personal and gender-based violence. No serious action is being taken to protect women in Uganda from violent partners. Most perpetrators escape detention due to endemic corruption in the police force and legal system.

The weaknesses in emergency care services are documented in our discussion of respondents' experiences of emergency care. These have a very direct impact on their subsequent health seeking behaviour and rehabilitation.

As with emergency services we had not anticipated the impact that systems failures in managing long term conditions and non-communicable diseases had on health seeking behaviour in prosthetic services. Patients' histories exposed serious problems in the Ugandan health system and real opportunities for preventive engagement to reduce amputation risk and the associated costs. Non-communicable disease (particularly diabetes and hypertension) is contributing to growing numbers of amputations. The lack of preventive attention to amputation reduction threatens health systems globally. Uganda needs to centre-stage this within the Rehabilitation Planning process as perhaps the greatest single challenge (and opportunity). Poor awareness of conditions, amongst health workers and the public, compounded by poor wound care across referral systems is contributing to avoidable and costly amputations. These have a devastating impact on individuals and reduce their ability

to engage in productive and revenue-generating work. Investment in early diagnosis and self-management programs for patients with diabetes and hypertension would significantly reduce costs to the Ugandan health system. Our current intervention exploring the potential for diabetes self-management in Uganda has demonstrated the opportunities that limited investment could make in reducing or delaying complications and amputation risk. The self-management program included the setting up of a dedicated and highly successful Diabetic Foot Clinic located in the Orthopaedic Workshop.[4] On the basis of our findings, both from the MRC project and the more recent Burdett Trust intervention we make the following policy recommendations.

Beliefs in witchcraft, 'juju' and non-traditional medicines appear to contribute to delays and amputation risk. Community based health workers should be encouraged to identify when inappropriate advice is given to patients concerning the causes of wounds and ulcers. Notably the belief in witchcraft as a cause which deters or delays accessing skilled health professionals. Fears about charging and lack of trust in public health facilities are key factors contributing to the resort to witchcraft and other forms of traditional healing. The authors are not in a position to advise against the use of traditional healers, but this should not be seen as an alternative to accessing public health services. Similar concerns were seen in the case of traditional bone healers (in Chapter 3). Whilst there is reference in the Strategic Plan to the need to develop on-going professional training for health workers through Continuing Medical Education (CMEs) there is scant reference to the value of embedding rehabilitation in existing (initial) education programs for all health workers and nurses, in particular. Managing the relationships between traditional beliefs and modern medicine would be an apt topic especially given the rise in NCDs.

Access to free basic medication to manage diabetes and hypertension is a key issue propelling patients directly into congested referral facilities. This contributes to high amputation risks and the costs to patients, the health system and the economy. Various forms of 'marketeering' involving collusion between government health workers and representatives of drug

[4] The results of the NEEDS program, funded by the Burdett Trust, are in the process of writing up.

companies[5] contribute to patient costs and poor adherence to medication. The development of community-based NCD clinics would support effective task-shifting, improve uptake, reduce costs and enable the RRHs to focus on complications arising from more advanced cases. The key to success would lie in ensuring access to medications at community level.

We now turn to address rehabilitation services more specifically.

Research, Information Systems and Evidence-Based Policy

The WHO report (2017) cited above contends that there is 'profound unmet need especially in LMICs'. The subsequent discussion about challenges faced refers, rather differently, to a, 'dearth of evidence on met and unmet need'. It also refers to 'projected increasing demand'. Chapter 1 reviewed some of the existing literature including Huck et al.'s work (2022) to map the prevalence and spatial patterns of major limb loss in the Acholi region of Uganda. In reality, at the present time, it is very difficult to estimate need (as in prevalence of physical disability) in a meaningful way. The Ugandan Strategic Plan cites figures suggesting that there are 768 people with lower limb amputations and 62,688 people affected by gendered-based violence; all of which share a 'burden amenable to rehabilitation'. These are not discrete categories, and we have no way of knowing if this 'need' equates to a demand for services. The figure of 768 does not sit very easily alongside Huck et al.'s estimation (extrapolated from a survey of 8000 households) of 10,117 people with major limb loss in the Acholi region alone (or 0.5% of the population). Unfortunately, the framing of the question on disability in the Ugandan Census doesn't enable us to enumerate limb loss as such. But the 2014 data, by way of example, showed that4.6% (or 20,100) citizens of Kabarole District had a 'walking disability'. Breakdowns of the latest 2024 Census data by disability are not yet available. However, available data show an overall population in Uganda of 45,935,046. If we extrapolate Huck et al.'s 0.5% that would indicate a figure of 229,675 people with major limb loss.

The same paragraph in the Strategic Plan refers to the 'absence of rehabilitation policies, rehabilitation facilities and equipment'. Where services

[5] These marketeers, as they are known in Uganda have free access to outpatient clinics and patient notes in the same way described by Sekyonda et al. (2018).

and associated funding do not exist, it does not make sense to expend significant resource and effort trying to enumerate need. Foreign organisations spend considerable time and resource trying to measure need and create complex registries for this purpose. At the present time this expenditure is not a priority in the Ugandan context. Resource may be better spent honing the questions in the existing Ugandan Census and Household Survey to improve capture of functional impairment. Need, in any meaningful sense, will only emerge when services are known about, affordable and accessible. It is interesting to note the lack of any reference to upper limb amputations in the Strategic Plan. Does the lack of available data imply lack of need?

The complex intervention has demonstrated the value of focusing on providing respectful services free of charge as a measure to demonstrate more genuine demand and understand the nuance of demand from a user perspective.

Key Action Areas 8 and 9 of the WHO Action Plan distinguish the need to improve health information systems from the need to build research capacity and generate robust evidence for rehabilitation. The rationale for collecting data on rehabilitation is described in the Ugandan Strategic Plan as a combination of advocacy (to lobby for resource) and accountability (to manage resource spend). The Report outlines a very ambitious range of indicators including numbers of 'rehabilitation beds'[6]; national rehabilitation expenditure; numbers of rehabilitation personnel; numbers of outreach programs and uptake of assistive products. It is difficult to design information systems before the health services themselves are in existence and particularly when the potential to allocate public funding to them is still very uncertain. From the point of view of physical impairment (and demand for mobility enhancing services) we would propose basing any plans to improve information systems on ensuring adherence to existing reporting systems and, where necessary, amending those systems incrementally as services evolve and demand becomes more evidence and better understood. As we have noted in Chapter 5, the Ministry of Health already has fit-for-purpose health information systems including HMIS reporting and mandatory 'Job Cards'. In reality, compliance is very weak and/or inaccurate. Plans to improve hospital procurement reporting are also actively in place. Incremental changes to

[6] Which currently do not exist in public hospitals.

extend reporting could easily be made as and when procurement extends to the products required in rehabilitation services.

Compliance with UMoH accounting systems is currently very poor and there is huge resistance to this process amongst health workers. This is unsurprising when services are so poorly funded. We have seen how the orthopaedic technologists in FPRRH continued to complete records at a time when they were unable to access any materials and had to simply write 'no materials' in the records book. It is also a time-consuming process and health workers often complain that they lack the time to undertake these tasks. The Strategic Plan describes current HMIS tools as 'already voluminous' (p. 9). Care will need to be taken to ensure that any enhancement of information systems focuses on the needs of the health workers responsible for reporting and are 'Fit-4-Purpose' and slim-lined.

This situation is exacerbated by demands from donors to complete bespoke and parallel information systems. Compliance with these is generally higher for fear of losing donor support and the wider implications of that.

Accountability systems in a health system riven with corruption are inevitably regarded with suspicion as surveillance mechanisms. This has the unfortunate effect of undermining trust in and valuing the purpose of information collection and the relationship between that information and access to human and physical resource. The present lack of any relationship between data on service productivity and deployment of human resource or provision of materials compounds this process (a point we return to below). Health information systems need to be valued by health professionals and be seen to play a positive role in performance review. They also need to be meaningful.

Our Complex Intervention has demonstrated the value (and efficacy of) collecting patient data from the orthopaedic workshop, but this has taken time and considerable investment in building trust and investing in people management. Alongside the HMIS data we have also invested in collecting data on the costs of manufacturing assistive devices. There is scant attention to service costs in the WHO or Strategic Planning documents or to measures to reduce the costs of device manufacture. Donnelley et al. (2021) used a systematic review process to identify research that analyses the costs of prosthetic devices. It is interesting to note that they were unable to identify any studies conducted in LMICs which, they contend, reflects the lack of prioritisation of rehabilitation in

countries with 'already strained financial resources. Neither did they identify any studies concerned with upper extremity prostheses (p. 1412). The authors conclude that context-appropriate studies are necessary for establishing the evidence-base needed to promote the provision of prosthetic services in LMICs' (p. 1412). Understanding the costs of devices and products is critical to the need for advocacy described in the Strategic Plan. Alongside this, we have argued that attention needs to be paid in all global settings to the issue of use and abandonment: 'Value4Money'. The Strategic Plan does include reference to 'Rehabilitation Effectiveness' (p. 36) citing 'client's average functioning assessment score'. It will be interesting to see how this translates and feeds into information systems. Combining qualitative interviews to capture patient feedback on services with activity monitoring could actively contribute to this process as services develop. Developing mechanism to gather feedback from the health workers themselves and embed them within the data collection process could help to build a sense of ownership and trust into systems. This data would also support the emergence of 'value-based' purchasing decisions. The overwhelming dependency on foreign 'donations' has excluded health professionals from such decision-making processes and any relationship with service costs.

The WHO Report also refers to the need for research and research capacity-building. There is little reference in the Strategic Plan to research and no published academic research is referenced in the Plan.[7] Our work has shown that there is a considerable amount of research taking place in Uganda on rehabilitation. Much of this is undertaken in research partnerships with colleagues in high income settings and is actively supporting the development of excellent early career researchers. A SWOT analysis included in the Strategic Plan does identify the 'availability of academia and researchers' as an 'opportunity' for future development. The opportunity is there for the Ugandan government to support the development of its own research community in this field and harness that research in the policy-making process.

[7] 12 of the 16 references refer to WHO reports.

Rehabilitation Facilities and Equipment

The WHO Call to Action refers quite explicitly to the 'absence' of rehabilitation facilities and equipment in many LMIC contexts. The reference is a stark reminder of the reality on the ground. It also signals a real opportunity; to build an infrastructure from scratch and avoid replicating the models developed in high income countries that are failing to deliver cost-effective services to meet extrapolating demand. The Ugandan Strategic Plan identifies some of the key systems that need to be put in place before services can begin to develop. These include improved infrastructure, access to products, procurement systems and supply chains. To the extent that infrastructure exists for physical rehabilitation in the Ugandan public sector this is in the form of the orthopaedic workshops attached to 13 Regional Referral Hospitals (Fig. 5.1). We have described the state of this infrastructure most of which is a legacy of humanitarian aid. As such it is very old and, in common with most equipment donations, consists of a vast range of equipment that donors made the decision to provide, usually without any consultation with technologists. This results in a proliferation of devices undermining the ability of local biomedical engineers to support effective maintenance and repair. The peripheral quality of these infrastructures coupled with donor policies (or the lack of them) compounds these problems as they are not seen as part of the wider hospital infrastructure. These problems with donated equipment in Uganda have led to the development of policies to prevent inappropriate donations and guide donors (Oshabaheebwa et al., 2020; Raxworthy et al., 2022).

The characterisation of existing equipment as 'largely lacking, broken-down or outdated' in the Strategic Plan (p. 15) captures the general context well. But this is not always the case and some of the public workshops have at least some functioning equipment. FPRRH is a case in point as we have described. The infrastructure is broadly fit-for-purpose, and the facility includes 12 in-patient beds in a residential unit. Where workshops have been supported by foreign partners, such as in Mulago and Gulu, infrastructure is in place. As noted in the Plan, some of the PNFP facilities have much higher quality facilities. The equipment required for prosthetic manufacture is expensive. At this point in time resource may not exist to fully equip all 13 regional workshops. The most immediate (and achievable) challenge to harnessing *existing* human resource in service delivery is the lack of any government funding for materials and devices. Our

evidence suggests this is the area where relatively small injections of public funding would most efficiently and immediately stimulate service provision in a carefully managed and evaluated process. The strategic planning team in Uganda is currently debating the configuration of a contextually appropriate Assistive Devices List.

In October 2023, the Strategic Planning team held a Consultation meeting, in response to the WHO Call to Action and specifically focused on developing the first Assistive Products List (APL) for Uganda. The APL is designed to 'guide the identification, procurement, and distribution of essential assistive products'. This marks an important step forward recognising the urgent need for supplies. Echoing some of the limitations of the WHO's APL[8] the discussion at the meeting focused on whole devices rather that materials required for local manufacture. When questioned about the rationale for this 'whole device' approach the consultant leading the meeting suggested that focusing on specific materials at this stage would make the list 'too bulky'. It is important to remember that the APL covers all aspects of rehabilitation and not just physical rehabilitation. Whole devices are the norm when it comes to eyecare or hearing aids and many other devices. Manufacturing devices for amputees demands deeper engagement with professional orthopaedic technologists who understand the processes involved. Inadvertently this 'oversight' could have serious unintended consequences for physical rehabilitation in Uganda and for the longer-term prospects for service quality (including user satisfaction and abandonment risk), cost-saving and in-country manufacturing innovation. Albala et al. (2021) 'more robust alternative evaluation and appraisal methodologies [are required] to make governments more willing to invest in and shape AT markets' (2021: S50) make point that they need to capture costs but also benefits from 'vantage point of patients, insurer, providers and wider societal perspectives'. A researcher respondent made the following comment:

> There are a few papers now pointing to the 'elephant in the room', a lack of robust clinical evidence for the vast majority of prosthetic devices. And an almost complete absence of cost effectiveness studies, except for certain (high cost) technologies, such as microprocessor controlled knee joints.

[8] The WHO APL mentions prosthetic devices (but not materials) and does not even mention upper limb prosthetics.

Donnelley et al. (2021) used a systematic review process to identify research that analyses the costs of prosthetic devices. It is interesting to note that they were unable to identify any studies conducted in LMICs which, they contend, reflects the lack of prioritisation of rehabilitation in countries with 'already strained financial resources. Neither did they identify any studies concerned with upper extremity prostheses (p. 1412). The authors conclude that context-appropriate studies are necessary for establishing the evidence-base needed to promote the provision of prosthetic services in LMICs' (p. 1412). Fast and low cost approaches to gathering evidence on 'what works' are needed. Chapter 7 discusses the potential to use a combination of activity monitoring and interviews to quickly gather key data on when/why people choose to wear/use their prosthesis and potential impacts on physical behaviours, such as walking. Further details on this approach can be found in xx.

The Strategic Plan glosses over the specifics suggesting that once the APL is approved a system of centralised procurement will take place and National Medical Stores will then distribute 'prosthetic devices' to the Regional Referral Hospitals (Fig. 4, p. 22). The evidence presented in this book presents the more complex reality of device manufacture and the critical need to build procurement policies and supply chains around a much wider range of materials, suppliers and distributors. Holloway et al.'s review of innovation strategies in the field of Assistive Technology makes the important point that '*market dynamics can be different across different categories of AT products, and individual markets might feature unique barriers and opportunities that affect their ability to thrive*' (2021: S68). Engaging technologists in the next stage of the APL process could enable this complexity to be captured by distributors (including NMS). This is also important in terms of ensuring that VAT-exemption applies to all materials and devices.

Human Resources in Rehabilitation

We have noted the constant reference in WHO documents and many other papers to global shortages both in terms of 'insufficient numbers and skills of rehabilitation professionals'. Almost every health system globally reports workforce shortages and, despite media attention to doctors, shortages are often felt most acutely in the Allied Health Professions. In the UK, for example, the AHP workforce is facing an acute recruitment

and retention crisis (HCPC, 2023). One in eight prosthetists and orthotists deregister within four years of qualification and over 37% express a desire to leave the profession (Prosser & Achour, 2023). NHS England has identified podiatry as facing particular skills shortages. In high income countries workforce crises may manifest in problems filling public sector positions. And the 'solution' to this is often articulated as a need to support increasing specialisation and career paths (and associated remuneration and recognition) focused on that. The unintended consequence of this specialisation 'solution' is to extract ever more health workers from direct patient care and increase the costs of services. It also creates a complex and misunderstood web of services for patients to negotiate.

It is important to note the quite different problem statement in the Uganda Strategic Plan which refers instead to workforce 'underutilisation':

> Despite having accredited rehabilitation professionals, Uganda faces the problem of underutilisation. Only a limited number of these professionals find placement in public service, with just 198 out of over 1,000 accredited by the Uganda Allied Health Professions Council [securing positions] in 2022. (2023: 6)

There is, in effect, a surplus of orthopaedic technologists in the Ugandan labour market with most diploma graduates facing unemployment or having to find jobs in other domains, often outside of the health system. It could be argued, on the basis of data on unmet need, that the key problem is the lack of government positions available. The Strategic Plan takes this view setting out an objective of 'expanding the rehabilitation workforce at all levels' (p. 12).

An interim solution to this could be requiring Regional Referral Hospital to recruit in line with their human resource plan. At present many of the positions designated for orthopaedic technologists are either unfilled or filled by cadres, such as doctors, not engaged in rehabilitation roles. This is certainly something to address in the future when demand for rehabilitation services increases. But this is dependent upon (and should follow in sequence with) a combination of wider resourcing commitments: funding rehabilitation infrastructure, equipment and supplies. There is absolutely no point in funding staff when they are unable to work. The current practice, of doing just that, actively stimulates and justifies endemic moonlighting and charging of patients.

The focus in the immediate term must be on finding ways to enable currently employed and skilled professionals to exercise and hone their skills by funding service provision. This will need to be done in tandem with very clear and enforced human resource management to require that staff are present during documented working hours and allowed not to be there outside of those hours. This requires a minimum staff complement to ensure staff cover during designated opening hours. The general 'prohibition' on private working is never enforced; heath workers expect it not to be enforced. A letter recently published by the Ugandan President (Museveni)[9] takes the shocking step of publicly dismissing an orthopaedic consultant on the grounds that, 'he does not work [and] is most of the time absent'. Museveni argues that the more relaxed approach to 'traitorous' public servants was tolerated due to the shortages of doctors. But as labour markets have changed and surpluses are evidence, he proposes the development of new standing orders to make disciplining health workers who misbehave 'easier and faster'. It remains to be seen whether this will lead to greater compliance with employment contracts. Museveni's letter includes a proposal to dismiss any Government doctor who owns or works for a private practice. On the basis of our experience, we would suggest that an outright and total ban on private work may prove hard to action and counter-productive. It may be better to permit private working explicitly within contracts to render it transparent with the proviso that it takes place independently of Government services and outside of normal working hours. Although the system in the UK and subject to constant scrutiny the Code of Conduct for Private Practice[10] enshrines 3 key principles:

- The provision of services for private patients should not prejudice the interests of NHS patients or disrupt NHS services;
- Agreed NHS commitment should take precedence over private work; and
- NHS facilities, staff and services may only be used for private practice with the prior agreement of the NHS employer.

[9] Dated October 16, 2024.

[10] Consultants and private practice (https://www.bma.org.uk/advice-and-support/private-practice/working-in-private-practice/consultants-and-private-practice).

Strengthening private services has the potential to enhance overall service 'offer', reduce pressure on public services and contribute to economic development. It needs to be transparent and managed. Achieving what seems, on the face of it, to be a simple 'recipe' will, in the wider context of human resource cultures in Ugandan public health facilities, be incredibly difficult to achieve. Powerful forces are at play to maintain the system as it is and tolerate moonlighting and corruption. Significant, highly publicised and sustained improvements in the management of existing human resource is urgently needed to ensure that every employee is able to and, required to work productively before further resource is committed. Failing to do so would be throwing good money after bad or, as a Commissioner for the UMoH put it, 'pouring old wine into new bottles'. Allocation of human resource should be linked to productivity (service demand). This will reduce moonlighting where there are no services and reduce inefficiencies caused by underemployed health workers. It will also motivate staff where services are functioning, to work efficiently in functioning teams.

It is common in the Ugandan health system for the same staff to hold more than one full-time position in public and private health facilities. For some this will involve two full-time jobs making it impossible for them to honour their contracts. In many others, a more peripatetic approach is deployed with doctors, anaesthetists and physiotherapists, for example, holding one public sector position but operating across a range of PNFP and PFP facilities. In other cases, including many orthopaedic technologists, staff will run private clinics or have a private workshop alongside their public sector position. To the extent that this private work does not prevent staff fulfilling their contractual commitments to their public sector employer or seek to 'poach' patients there is in principle no problem with this approach. Unfortunately, the conflation of these roles and association of any private work with 'moonlighting' pushes the private sector underground and creates a smokescreen around services.

Much stronger enforcement of human resource management in public services could solve this problem. At the moment, heath facilities find it impossible to require staff to meet their contractual obligations. Employers have the 'right' not to pay staff who attend for work less than 15 hours per week. In practice this has created an expectation amongst staff that working 15 hours is all that is required, and many will absent themselves for extensive periods and not even have to account for their absence.

We have already raised concerns about the pressure for specialisation. Much of this pressure comes from foreigners often motivated to replicate systems in their own occupational cultures and health systems. It is common to hear foreign partners call for more degree and master's level qualifications in response to a perceived 'skills gap'. And yet this approach has done nothing to solve skills gaps in those systems rather promoting exit from hands on clinical work and lubricating both internal (intersectoral) and international 'brain drain'. The return to more apprenticeship models of health education in the UK is a direct response to this.

In the case of orthopaedic technologists who are currently the main cadres staffing orthopaedic workshops in Ugandan regional hospitals our experience suggests that the current task-shifted (generalist) model is absolutely fit-for-purpose and high-income countries have much to learn from it.

It is interesting to note that the Ugandan Strategic Plan does not mention orthopaedic technology as part of the rehabilitation workforce. It describes the 'functional domain' of 'mobility' as staffed by a number of 'core services' including prosthetists and orthotists,[11] occupational therapists and physiotherapists. It goes on to state that 'most of the rehabilitation workforce comprises a single discipline, physiotherapy' (p. 13). The reliance on physiotherapy is then interpreted as creating 'wide gaps in rehabilitation services which are either not addressed or are addressed by other health personnel who may be inadequately trained or specialised' (p. 14). Our experiences suggest that, to the extent that rehabilitation of people with limb loss takes place at all in public referral hospitals, this is done holistically by orthopaedic technologists and physiotherapists and (the very few) occupational therapists focusing on other aspects of healthcare.

In response to this concern, the Plan proposes the recruitment of over 1500 professionals with a focus on enhancing training capacities for 'intensive and specialised rehabilitation services' referring specifically to occupational, speech and physiotherapy. The words 'intensive' and 'specialised' are interesting in this context and detract somewhat from the need for task-shifted, generalist support services provided continuously

[11] These professions and the education programs to generate these cadres do not currently exist in Uganda.

over the life course. This neglect of orthopaedic technology and overriding emphasis on specialisation also sits uneasily alongside the essential commitment to developing rehabilitation services and workforce 'below RRH level' in community health centres. It is interesting to note that, in this context, the report actively advocates 'task-shifting' with other professionals and even Village Health Workers. Our study would actively support this emphasis both in terms of improved first aid, wound care and early diagnosis and management of diabetes and hypertension. Given current staffing regimens we would argue for a strong emphasis on task-shifting to nurses who form the overwhelming majority of task-shifted staff in community health facilities. It is noteworthy that the WHO Call to Action makes scant reference to nursing – apart from one reference to 'rehabilitation nursing' (p. 4) and home nursing (which is not currently relevant in Uganda). Whilst the call for specialisation is, in our experience, inappropriate and may have powerful externality effects there is a need for a standardised, Uganda-led, professional development program. As noted in the Strategic Plan this should be supported by invigorated professional bodies but working across them to promote multi professional learning. Continuing Professional Development or Continuing Medical Education (as it is termed in Uganda) is largely unfunded and often dictated by foreign partners or donors (a point we return to below).

Financing Systems

As we have noted, moving from a situation of zero financing for infrastructure, equipment and materials to achieving a sustainable, independent,[12] public rehabilitation services implies a major reallocation of public health resource. The Ugandan Strategic Plan inevitably makes the case for the allocation of 'sustainable financing' (p. 12). In support of this and in an attempt to reduce overall costs (rather than provide finance directly) it refers to the need to extend VAT exemptions on AT procurement. It also refers to the need to 'ensure coverage by the National Health Insurance Scheme' (see below) and gaining support from Public–Private-Partnerships but provides no detail on what these may look like. Apart from the reference to 'prioritisation' of rehabilitation the Report falls short of suggesting where the much-needed public funds could come

[12] We deal with issues of donor dependency and partnership integration below.

from. We have made the case for a focus, in the first instance, on measures to drive down the unit costs of device manufacture through supply chain innovation and market shaping activities. This is, in our view an absolute priority as the prices currently paid for a very limited range of products are extremely high. Shifting resources from other areas of health care to rehabilitation (as the pot is finite) demands a greater degree of advocacy. Generating a robust evidence base to demonstrate the impact of investments in rehabilitation on patient well-being, productivity and health and economic systems has a major role to play in this process. Mechanisms such as the activity monitoring discussed in Chapter 7 have an important role to play in this process.

So too do very clear and actively enforced transparency systems to put a stop to the haemorrhaging of government investment through corruption. We can anticipate that corruption will have a major impact on rehabilitation services and particularly those associated with expensive procurement. Before any new investment is committed the government must take active and robust measures to identify and enforce existing breaches of rules. Concerns about corruption and inefficiencies in NMS supply chains with reported losses of up to 60% of product, constant stock-outs and extensive delays in orders reaching hospitals raise issues about reliance on one monopolistic national supplier. These would need addressing before considering the procurement of what are very high value items. There is also a common concern, among health professionals, that NMS procures on the basis of price alone often buying the cheapest product irrespective of the views of health professionals and whether the product is Fit-4-Purpose. In the case of prosthetic devices this will simply lead to abandonment and waste.

We have argued above that expenditure on establishing overall 'need' is probably not the best use of resource at this point in time as this information, on its own, is unlikely to leverage the funding required to support service development.

The state of the current infrastructure also indicates the need for a robust assessment of infrastructure needs at all 13 regional workshops. The resource implications are so overwhelming, and the evidence base so weak at present we would propose an incremental approach focusing on the trial of a public resource package at 3–5 Regional Hubs. Assessment of resource requirements could be based on the intervention reported on in the FPRRH Workshop and the level of materials use and materials procurements. This would also enable demand to be tracked over time

and support the engagement of health professionals and service users in future service planning.

The Ugandan Strategic Plan refers to the role of 'outreaches' as one of the possible metrics for health information systems ('number of rehabilitation sessions provided by outreach programs' (p. 35). This is the only reference to outreach and the concept is not detailed as such. We have described the feedback of users and health workers on ad-hoc outreach approaches and the huge sustainability concerns especially where vehicles, fuel and transport allowances are required. This statement however, sits alongside reference to the provision of an 'essential package' at Health Centre IV level suggesting it is considered part of planned referral innovations. Using VHTs to engage in actively in outreach to sensitise the public about services and prevention has been shown to play an important role in stimulating health seeking behaviour (Auma et al., 2023). In the longer term, as the overall demand for rehabilitation services increases and, if there is a genuine commitment to preventive intervention especially in relation to NCDs, then managing this demand and ensuring that referral hospitals are not overwhelmed will require much greater involvement of community health facilities and strengthened nurse leadership in that context.[13]

Liao et al. (2020) suggest that the high indirect costs for users to travel to access prosthetic services undermines access. On that basis they suggest that increasing the number of service units by leveraging decentralised service models will improve affordability. They also propose establishing reimbursement schemes that encapsulate all costs to the user, including travel and subsistence. While this could form part of an ultimate objective, our findings do not support this model in Uganda at this point in time. Under the existing funding envelope transport refunds and support for subsistence during rehabilitation are not sustainable. These types of funds are highly vulnerable to corruption. Users can plan for these costs if they know services are free and effective. Decentralisation could further dissipate services. The first step should be to functionalise a number of HUB workshops and focus on providing more holistic and reliable free services at those. Once these services are working effectively and known about investment in feeder referral centres could work well. Awareness of

[13] As part of our diabetes self-management program K4C is supporting the establishment of a diabetes and hypertension clinic in a Health Centre 3 facility that refers into FPRRH.

services and consistency in service costs and quality are key to access and affordability. Awareness raising programs should be carefully planned to ensure realistic workloads for the functioning facilities and appropriate human resource support. In the short term that could mean reallocating staff to a smaller number of regional workshops, supporting the infrastructure in those and providing a budget for materials.

Partnerships in Rehabilitation

The previous section noted the aspirations that Public–Private-Partnerships in Health (PPP/H) might have a role to play in financing rehabilitation systems in Uganda. The WHO Call to Action refers specifically to the need for 'partnerships in rehabilitation, particularly between low-, middle- and high-income countries' (Area 10). Area 3 also refers to the need for service integration and improved inter-sectoral links. Although these issues are inevitably conjoined it is useful to separate out these dimensions of partnership in the first instance.

We have argued strongly that Uganda is a country of haves and have-nots, and this is reflected in the co-existence of often high quality and lucrative private health services that sit alongside PNFPs and the public sector. All global health systems to a greater or lesser degree can be described as mixed economies with those citizens that can often 'choosing' to use their own pockets or private insurance schemes to access what they perceive to be higher quality services. There is nothing in the concept of Universal Health Coverage that states that all citizens should receive exactly the same services. Although mixed economies respond to and generate inequalities, the priority in LMICs should be to ensure that all citizens have access to affordable and acceptable services.

In mixed economies, not only can patients move between sectors in order to access services. Government funding can also move; and various PPP/H agreements exist where the government co-funds PNFP services. A more strategic approach to this, combined with clear rules and service-charging could bring greater efficiencies into service planning and reduce some of the wasteful duplication that exists. A more complex issues arises when we consider the 'moonlighting' issue (discussed above).

User-Fees

We have noted concerns about how any future plans for rehabilitation services will be financed in the Ugandan context. Figures from the Ugandan UMoH in 201 suggest that only 17.2% Current Health Expenditure in Uganda comes from government sources; 41.4% is described as 'donor support' and a further 41.4% (as domestic private health). In this context and given the experiences of our respondents of both emergency and long term care, the prosect of reallocating moving funds from other areas of health care will present major challenges and is highly unlikely to happen. It would indeed be hard to justify such resource reallocations on ethical grounds. The very high proportion of donor support is typically assigned to and, perhaps inevitably, silo'd within specific funding domains and projects and not available for UMoH reallocation as such. This underlines our emphasis on cost reduction and more efficient use of human resource. It also raises the complex ethical issues around patient contributions to service costs.

Uganda is the only country in East Africa not to have passed a national health insurance scheme. Current employer or community-based schemes are estimated to cover less than 2% of the population (Basaza et al., 2009). In 2021, Health Minister Dr Ruth Aceng argued persuasively that the notion that healthcare should be free of charge is hindering progress on Universal Health Coverage in Uganda:

> Health is expensive. I have moved to many places in this world. I have never found where health services are given free of charge except in Uganda. We are hiding our heads in the sand and pretending that services can be free.

In 2021 the Parliament of Uganda passed a National Health Insurance Bill that outlines the structure for a first-ever national social health insurance scheme.[14] However, the President is yet to sign the Bill into law. This achievement comes after decades of engagement and consultations

[14] Parliament of Uganda Passes the National Health Insurance Scheme Bill | JHU—Advance Family Planning (https://www.advancefamilyplanning.org/parliament-uganda-passes-national-health-insurance-scheme-bill).

between civil society and government stakeholders. Aceng advocates fast-tracking this process, 'because it is the only way we are going to mobilise additional resources for health'.[15]

The other option is to reconsider the blanket ban on user charges in the public sector. This is particularly poignant when we accept that there are indeed no free services in the Ugandan public health system and user charges are the norm. Our findings suggest that the current total ban on permitting patient fees is counterproductive. It is also, quite simply, untrue. As Sekyonda et al. point out, 'although services in public health-care institutions are ostensibly free of charge, this is almost never the case' (2018: 1).

We have noted the Ugandan Ministry of Health's decision not to fund the provision of infrastructure, equipment, materials, and componentry in the Public Regional and National Orthopaedic Workshops. We have also documented the huge sums the majority of patients pay in accessing emergency and routine healthcare in Ugandan Private, PNFP and Public Services. Patients accessing the public health sector expect to be asked to pay for drugs, materials, blood, operations, and respectful care (Ahmed et al., 2017). One of the reasons patients turn to the private sector, where charging is formalised, is the uncertainty about who and what to pay in public services; corruption is opaque and, as we saw in the case of amputations, there is no logic behind charging systems. It is quite normal for health workers to apply a 'visual means test' or what some people refer to as the 'blanket test' and make decisions on whether to treat, how much respect to show and how much to charge accordingly (Ackers et al., 2018).

In spite of widespread awareness of the endemic quality of corruption, the Ministry of Health adheres to its principle that public healthcare in Uganda is free at the point of use. To enforce that principle (whilst also failing to even begin to tackle corruption) it does not permit patients to formally contribute to services. Whilst there is some logic to this situation, in the context within which it is deployed, it leaves people without services and facing major delays in accessing care. It also deprives those people reliant on public services of any choice. We have also noted the 'Cinderella' status of preventive and rehabilitation services in Uganda and the inherent logic in focusing finite resource on emergency and critical care.

[15] Daily Monitor, April 1, 2021, https://www.msn.com/en-xl/africa/top-stories/doctors-ask-govt-to-expedite-national-health-insurance-scheme-bill.

Regional Referral Hospitals in Uganda are in a state of perpetual 'crisis' exhausted by the pressure to deliver critical care. In that context how do we justify diverting resource to rehabilitation—or even prevention? It is in this environment that Ugandan health workers make the case for allowing patients to make an out-of-pocket contribution to rehabilitation services, which are by their nature resource intense. A Ugandan-based distributor respondent argued strongly for the re-introduction of user-fees on the grounds that this could help to fund public workshops, encourage patients to value their devices more and build market demand:

> A user fee should be introduced in the public workshops for the patients to feel that this is my item, and I should not misuse it. There is no realistic way to keep providing these services unless patients contribute some money unless we want to keep donors here. The moment the hospital introduces user fees for rehabilitative services, it should be committed to making that money available in case there is a need for components and materials. If they put all the money collected in one granary, of course, malaria and maternity will take priority. Rehabilitation will never be a priority once the funds collected from user fees are put in one pot. If we can introduce a user fee, then it becomes easier for the workshops to have funds. Then the private sector can supply those items. And probably when the government gives them something they can use that as well. (D10)

The respondent is emphatic about the risks that any fees may be syphoned into other services. He also suggests that user fees could go hand-in-hand with public investment. It is clear from our findings that the alternative to user-fees is not free services but paying high costs in the private sectors or facing, often more expensive and unpredictable, complex corruption rackets. Or receiving no health care and the consequences of that. There is also a pressing ethical issue about consumer choice in a society where not everyone is poor. We can anticipate growing demand from those users who can contribute for the more expensive products available on global markets. This will create complex and ethically challenging discussions about the relationship between needs and wants and the role of public welfare in the delivery of these. Poverty and inequality no longer shield people from exposure to opportunities and technologies available to others. This is true especially for health workers in Uganda who are actively exposed to devices available on international markets. Both health workers and patients also readily access the internet gaining exposure to global opportunities. One of our distributor respondents (a prosthetist

working in Tanzania) explains how her patients are exposed to the availability of silicone liners for example. She sees a growing demand from patients to be allowed to pay for what they perceive to be higher quality technology:

> I now see amputees wanting to buy silicones to have the fancy stuff. A prosthesis has an outer hard-shell. You're supposed to have an inner soft core which you can make using different materials. Or you can have it from silicone. It's more comfortable and softer and dissipates pressure so they're at less risk of getting blisters or ulcerations. Patients value the ability to pay or top-up for extra choice. (D04)

International Partnerships

The second aspect of partnership concerns what are popularly now termed International Health Partnerships. We have noted the huge undercounted share of health expenditure[16] that comes from these sources. Concerns about the quality of relationships and balance of power involved in many forms of foreign engagement in global health have led to increasing discussion about the ethics of health partnerships. The UK's Tropical Health and Education Trust is one of many organisations to have defined its 'Principles of Partnership'.[17]

The Ugandan Strategic Plan calls for greater coordination and more joined-up planning to integrate overseas engagement in national health systems planning. It identifies heavy reliance on project-based funding and inconsistent donor support as a 'hindrance to sustained provision' (p. 6). The evidence presented in this book would reaffirm that analysis. Ultimately, reducing reliance on donors is best remedied by committing public finance to rehabilitation. But in the context of substantial dependency and acute resource scarcity can a health partnership model improve the integration and efficacy of overseas aid and donorism and, critically, reduce some of the externality effects associated with it? The following section discusses some of the challenges and opportunities to improve health partnership working and the potential for multilateral knowledge mobilisation that exists.

[16] Funding for most smaller NGO providers, including K4C's work, for example, will not be part of the overall enumeration.

[17] Principles of Partnership—THET (https://www.thet.org/principles-of-partnership/).

Our research experience including work on the management of NHS volunteers and students has led us to ask all colleagues working with us in Uganda to reflect: 'Would you accept this kind of intervention at home?'. The generation of parallel services is a case in point or outreach services. Liao et al. (2020) describe how, 'in the absence of government investments, NGOs have developed service capacities, largely in response to emergencies that sometimes operate in parallel to government systems'. We would encourage partners to consider, in the first instance, using the resources available to strengthen the Ugandan public health system as this is the best and only sustainable way of delivering integrated Universal Health Coverage. Of course, it is much easier and often more satisfying to donors to establish parallel PNFP services. And it avoids the daily debilitating impact of endemic corruption. But how sustainable are these services. And are the partnerships with PNFP providers genuinely not-for-profit or is PNFP status a smokescreen for private gain? A proliferation of random and sporadic donor interventions may help to meet the needs of a small number of individuals, but this does not support a national commitment to comprehensive Universal Health Coverage. The specification of populations for receipt of donor services also undermines Universal Health Coverage. What appear to be positive ethical (or grant-winning) priorities from the perspective of a High-Income Country can have seriously discriminatory consequences. This is a particular concern with funding for refugee organisations which inevitably draw on public resource and leave Ugandan citizens behind. They may also generate political unrest.

We have witnessed the damaging impacts, inefficiencies and poor outcomes associated with many outreach programs. A concern here is the sporadic quality of many of the one-off outreach initiatives where fitting is rushed and post-fitting rehabilitation or opportunities for repairs or replacements, non-existent. This approach does not reflect the continuous quality that life-long rehabilitation demands.

Some of these limitations can be overcome by more systematic and repeated outreach from existing workshops into rural and hard-to-reach communities. The key problem here is the reliance on donor support for vehicles and fuel and top-up per diem payments to existing public sector employees. Public funding is extremely unlikely to pick up the costs of transporting staff in this way and the payment of per diems to government workers, often without the permission or knowledge of their

employers actively contributes to absenteeism and takes staff away from their designated workplaces.

We have also devoted some attention to the perception that the key challenge to rehabilitation services lies in a lack of expertise amongst local health workers. This is a popular assumption in global health often arising from a very shallow engagement with services and false interpretation of health worker behaviours. It also lends itself to 'quick fix' self-gratifying responses that reinforce the 'West knows best' rationale for a proliferation of uncoordinated, patchy and often duplicated 'trainings'. We have reported elsewhere on this dynamic and the consequent association of training, by health workers, with remuneration (Ackers-Johnson & Ackers, 2016). So-called per-diemism has escalate the costs of delivering training in global health. It is gratifying to see that many of the more aware organisations now ban per diems (THET, for example). We have actively advocated the use of on-the-job or bedside mentoring and bite-size training to meet needs articulated by local health workers (Ackers et al., 2022). Widespread, normalised, but inappropriate foreign training taking place in expensive hotel venues and lubricated by per diems and transport allowances has had a major distorting effect on knowledge mobilisation processes and the costs involved. One of the reasons for this approach is the lack of comprehensive national Continuing Professional Development programs controlled by relevant professional associations. Supporting the development of more standardised programs is a much better way of utilising resources in staff development.

One of the other problems with donorism referred to in this book concerns the provision of materials, equipment and devices. A key concern here is the ways in which foreigners make unilateral decisions about which technologies and materials they want to provide without consulting the local staff who will be asked to use those materials. Resort to such 'in-kind' approaches to donation need to be understood in the context of widespread corruption. Not only have most foreigners learnt that making cash contributions almost always results in losses but most Ugandan health workers and managers will explicitly ask that cash is not given. This reflects their experiences that cash, once in the 'system' will be extraordinarily difficult to spend and highly vulnerable to corruption.

Public–Private-Partnerships based on high levels of trust and transparent accountability systems are, at present, the best way of dealing with this situation so that neither the health workers nor the hospital managers have to handle cash directly.

In the long term, all materials and devices will need to be sourced through in-country supply chains and systems need to be put in place to ensure optimal efficiency. For the time being there is a case to be made for recycling componentry that would otherwise be committed to land fill as a result of the inefficiencies and risk management process at place in high income settings. Whilst valuable and reusable componentry is greatly needed in LMICs and can be put to extremely good use, it is important to avoid wholesale 'dumping' of second-hand equipment and devices on LMIC organisations. There is often insufficient capacity to manage and maintain donated equipment and devices leading to huge (and expensive) problems of decommissioning and disposal. Where strong and trusted health partnerships are in place and accountability systems co-owned by all parties the distribution of second-hand componentry can considerably reduce the costs of manufacturing prosthetic devices and dealing with the waste associated with healthcare in HICs.

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Index

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