BUILDING CHILD SAFE COMMUNITIES WITH CHILDREN AND YOUNG PEOPLE AT THEIR HEARTS

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CONTENTS

CONTENTS I
LIST OF TABLESIX
LIST OF FIGURESXI
DEDICATIONXIII
ACKNOWLEDGMENTSXIV
CORE PUBLICATIONSXV
SUPPLEMENTARY PUBLICATIONSXVI
DECLARATIONXVII
AUTHORSHIPXVIII
ABBREVIATIONSXX
ABSTRACT 1
1: INTRODUCTION TO THE THESIS 2
AIM
OBJECTIVES
2: BACKGROUND (WIDER DISCIPLINARY PERSPECTIVES) 4
INTRODUCTION 4
CHILDREN'S ADVOCACY 4
CHILD RIGHTS 8
LEGISLATION 17

	Introduction	17
	Female Genital Mutilation	18
	Physical Punishment Of Children	19
C	CHILD HEALTH	22
	The State Of Child Health In The UK	22
	Early Warning Scores And Systems In Children's Emergency Medicine	25
	Defining Significant Childhood Illness And Injury In The Emergency	
	Department	27
	Efficacy Of Rectal Paraldehyde: An Example Of Clinical Child Health	
	Research	28
S	SUMMARY	30
3:	METHOD	33
I	NTRODUCTION	33
F	RESEARCH METHODS	33
C	CORE PUBLICATIONS	35
	Core Paper (1)	35
	Core Paper (2)	38
	Core Paper (3)	41
	Core Paper (4)	44
	Core Paper (5)	46
	Core Paper (6)	50
	Core Paper (7)	53
S	SUPPLEMENTARY PUBLICATIONS	58
S	SUMMARYii	62

4:	CRITICAL APPRAISAL OF CORE PUBLICATIONS	63
		63
	PAPER (1): PHYSICAL PUNISHMENT OF CHILDREN	64
	Background	64
	Method	65
	Limitations And Critical Reflection	65
	Results	66
	Conclusions	68
	PAPER (2): MANDATORY REPORTING OF FEMALE GENITAL	
	MUTILATION	71
	Background	71
	Method	72
	Limitations And Critical Reflections	73
	Results	73
	Conclusions	74
	REPORT (3): NOT JUST A THOUGHT	76
	Background	76
	Method	78
	Limitations And Critical Reflections	79
	Results	82
	Next Steps	83
	REPORT (4): CHILDREN'S ADVOCACY HOUSE CONSULTATION	85
	Background	85
	Method	86

Limitations And Critical Reflections	88
Results	89
Conclusions	90
PAPER (5): DEFINING SIGNIFICANT ILLNESS AND INJURY IN THE	
EMERGENCY DEPARTMENT	90
Background	90
Method	91
Limitations And Critical Reflections	92
Results	93
Conclusions	94

PAPER (6): DIAGNOSTIC ACCURACY OF PAT-POPS AND MANCHEWS

FOR ADMISSIONS OF CHILDREN FROM THE EMERGENCY

DEPARTMENT	94
Background	94
Method	95
Limitations And Critical Reflections	96
Results	98
Conclusions	98
PAPER (7): REFINING AND TESTING THE ACCURACY OF PAT-POPS	б то
PREDICT ADMISSION AND DISCHARGE OF CHILDREN AND YOUNG	
PEOPLE WHO ATTEND AN EMERGENCY DEPARTMENT	99
Background	99
Method	101
Limitations And Critical Reflections	103
Opt-out Consent Model	104

5 <i>:</i>	CONTRIBUTION TO KNOWLEDGE AND THE UNIFYING MODEL	107
I	NTRODUCTION	107
L	AWS PROTECTING CHILDREN AND YOUNG PEOPLE	108
C	CHILDREN'S ADVOCACY	111
	Living On A Railway Line	111
	Not Just A Thought	112
	Advocacy House	113
F	PRAGMATIC CHILD HEALTH RESEARCH	114
	Paraldehyde	114
	Significant Childhood Conditions	115
	Early Warning Scores And Systems	116
٦	THE UNIFYING MODEL	117
6 <i>:</i>	KEY MESSAGES AND IMPACT	121
N		
	MESSAGES FOR RESEARCH AND SOCIETY	121
	Female Genital Mutilation	
		121
	Female Genital Mutilation	121 122
	Female Genital Mutilation Physical Punishment Of Children	121 122 122
	Female Genital Mutilation Physical Punishment Of Children Legislative Change Required	121 122 122 122
I	Female Genital Mutilation Physical Punishment Of Children Legislative Change Required Children's Advocacy	121 122 122 122 123
I	Female Genital Mutilation Physical Punishment Of Children Legislative Change Required Children's Advocacy Emergency Child Health	121 122 122 122 123 123
1	Female Genital Mutilation Physical Punishment Of Children Legislative Change Required Children's Advocacy Emergency Child Health MPACT	121 122 122 122 123 124 124
I	Female Genital Mutilation Physical Punishment Of Children Legislative Change Required Children's Advocacy Emergency Child Health MPACT Launch Of A New Charity (SicKids)	121 122 122 122 123 124 124 125

	ChildSafe Accreditation	127
	Partnership Working In Cambodia	127
7:	FUTURE PLANS	129
F	PUBLICATIONS SUBSEQUENT TO THE CORE AND SUPPLEMENTAR	Y
F	PUBLISHED WORKS IN THIS THESIS	129
	Unlocking Children's Voices During the COVID-19 Pandemic Lockdown	129
	FGM Protection Orders	131
F	PUBLICATIONS UNDER REVIEW OR IN-PRESS	132
	Opt-out Consent In Children's Emergency Medicine	132
	Inter-rater reliability of emergency assessments of vital signs and clinica	I
	features of children: direct observation method	133
	Development Of A Multivariable Prediction Model And Scoring Tool For	
	Identification Of Children In Need Of Hospital Admission From The	
	Emergency Department: the [PAT-POPS Version 2 Tool]	134
F	RESEARCH GRANTS SUBMITTED	135
	Music In Children's Emergency Departments (MusIC-ED): An Explorator	ry
	Study Following The SARS-CoV-2 (COVID-19) Pandemic	135
	Is My Child Sick? Post-COVID-19 Children's Emergency Physiology (CE	EP)
	In Urgent Care Settings	138
F	UTURE STUDIES	141
F	PERSONAL AMBITION	142
8 <i>:</i>	CONCLUSIONS	144
RE	FERENCES	147

APPENDIX ONE	4
AUTHORSHIP OF INDIVIDUAL PUBLISHED WORKS	4
Core Published Work (1) 174	4
Core Published Work (2) 174	4
Core Published Work (3) 175	5
Core Published Work (4) 175	5
Core Published Work (5) 175	5
Core Published Work (6) 176	6
Core Published Work (7) 177	7
Supplementary Published Work (8) 177	7
Supplementary Published Work (9) 177	7
Supplementary Published Work (10) 179	9
Supplementary Published Work (11) 179	9
Supplementary Published Work (12) 179	9
AUTHORSHIP EVIDENCE	1
APPENDIX TWO 184	4
DEFINING SIGNIFICANT CHILDHOOD ILLNESS AND INJURY IN THE	
EMERGENCY DEPARTMENT: A CONSENSUS OF UK AND IRELAND	
EXPERT OPINION	4
Conditions Achieving Positive Consensus 184	4
Condition Achieving Negative Consensus 197	1
Conditions Achieving Non-Consensus 197	1
APPENDIX THREE	4
THE PUBLISHED WORKS 194	4

Core Published Works	194
Supplementary Published Works	196

LIST OF TABLES

Table 1: Core publicationsxv
Table 2: Supplementary publicationsxvi
Table 3: Summary of Andrew Rowland's contributions to the published works xix
Table 4: Abbreviationsxx
Table 5: Universal Human Rights
Table 6: The Articles of Section 1 of the European Convention on Human
Rights 12
Table 7: Articles of the United Nations Convention on the Rights of the Child. 14
Table 8: Methods used in the portfolio of published works
Table 9: Illness or injury conditions reaching ≥80% positive consensus for
warranting acute admission to hospital 185
Table 10: Statements (illness or injury) which did not reach consensus (≥80%
for warranting acute admission to hospital)192
Table 11: Core published works underpinning this thesis 194

Table 12: Supplementary published works supporting this thesis 196

LIST OF FIGURES

Figure 1: Examples of factors that may impact on the ability of a child to be
involved in decisions regarding their healthcare
Figure 2: Key findings from the RCPCH State of Child Health 2020 report 23
Figure 3: ALSG algorithm for the management of status epilepticus in children
Figure 4: Seven steps to protecting children and young people 111
Figure 5: Children's Law, Advocacy and Health 118
Figure 6: Improving outcomes for children and young people
Figure 7: Micro- and Macro-Advocacy 119
Figure 8: Integrated children's health and social wellbeing
Figure 9: Child safe communities with children and young people at their hearts
Figure 10: Letter 1 from Dr Donna Peach 181
Figure 11: Letter 2 from Dr Donna Peach 181

Figure 12: Letter from Professor Felicity Gerry QC	182
Figure 13: Letter from Marcia Stanton MSW	183
Figure 14: Letter from Professor Tony Long PhD	183

DEDICATION

This thesis is dedicated to my parents Denise Rowland MBE JP and James Rowland. Their outstanding love, support, encouragement and kindness throughout the whole of my life has enabled me to achieve everything that is set out in this thesis, and more.

This thesis is also dedicated in memory of my grandparents Frederick Langley Noble ("Fred"), Elizabeth Noble (née Bradley), Thomas Rowland and Mary Rowland (née Moses).

Fred and Elizabeth shared a birthday, were married to each other for over 70 years, and died within three days of each other two years after I became a Consultant in the National Health Service^{1 2}. I know they would have been immensely proud and delighted to read this thesis and to have a Doctor (squared) in the family!

Mary died just before I went to University to study Medicine and Thomas died before I was born. However, I am sure that they too would also have been extremely proud of the success and achievements described in this thesis.

Without the collective support, encouragement, enthusiasm, generosity and interminable kindness of all of the above individuals (parents and grandparents alike) the background work leading up to the published works cited in this thesis, and the writing of this thesis itself, would not have been possible.

Thank you very much.

Andrew

¹ <u>https://www.thenorthernecho.co.uk/news/10676324.couples-touching-love-story-to-be-shown-on-antiques-roadshow/</u>

² <u>https://www.mirror.co.uk/news/uk-news/newlyweds-passionate-wartime-love-letters-2275417</u>

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I want to especially acknowledge the support of Captain Neal Redshaw, Mr Den Carter, Dr Remy McConvey, Dr Michael Daley and all of my wider circle of close friends for your tolerance, patience, kindness and enthusiasm during the countless hours I have spent preparing both this thesis and the background material associated with it. Thank you all!

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Thank you to the team at the Winston Churchill Memorial Trust for your support and mentorship over the last six years. There is no doubt in my mind that my Churchill Fellowship has had a profound, enduring and, I anticipate, life-long positive effect on me as an individual. My Fellowship has given me much more confidence to speak out about my own values and the things that are important to me, in the knowledge that when doing so I often have significant skills and experience to contribute, many of which have been developed as a result of my Fellowship. Churchill Fellowships are superb opportunities for professionals to work on an idea that really matters to them. They offer a novel opportunity to obtain funding outside of a rigid set of rules and guidelines.

I hope you enjoy reading this thesis as a follow-up publication to both *Living on* a *Railway Line* and *Life on the tracks*. It was written with Sir Winston Churchill's words at the forefront of my mind, "*what is the use of living if it be not to strive for noble causes and to make this muddled world a better place for those who will live in it after we are gone?*".

CORE PUBLICATIONS

The core publications set out in **Table 1** are the published works upon which this thesis is primarily based.

Table 1: Core publications

Label	Title of work	Theme
Paper (1)	Physical punishment of children: time to end the defence of reasonable chastisement in the UK, USA and Australia	Law
Paper (2)	Mandatory Reporting of Female Genital Mutilation in Children in the UK	Law
Report (3)	Not Just a Thought	Advocacy
Report (4)	Outcomes from the Children and Young People's Advocacy House Consultation Event – MediaCityUK	Advocacy
Paper (5)	Defining significant childhood illness and injury in the Emergency Department – a consensus of UK and Ireland expert opinion	Health
Paper (6)	Diagnostic accuracy of PAT-POPS and ManChEWS for admissions of children from the emergency department	Health
Paper (7)	Refining and testing the diagnostic accuracy of an assessment tool (PAT-POPS) to predict admission and discharge of children and young people who attend an emergency department: protocol for an observational study	Health

SUPPLEMENTARY PUBLICATIONS

The author of this thesis has published a number of works which are relevant to the thesis, as they provide additional information or perspectives on the core published works included in the portfolio. These additional (supplementary) publications set out in **Table 2**. They are published works which support and underpin the core publications within this thesis, although they are not part of the primary compendium of published works upon which this thesis is based.

Table 2: Supplementary publications

Label	Title of work
Report (8)	Life on the tracks
Report (9)	From sick kids to SicKids!
Published Letter (10)	Failure to evaluate introduction of female genital mutilation mandatory reporting
Report (11)	Living on a Railway Line: Turning the tide of child abuse and exploitation in the UK and overseas: international lessons and evidence-based recommendations
Paper (12)	Review of the efficacy of rectal paraldehyde in the management of acute and prolonged tonic-clonic convulsions

DECLARATION

I, <u>Andrew Graeme Rowland</u>, declare that I have read and understood the University of Salford Policy on Academic Misconduct and that

- 1. The work in this thesis is my own;
- 2. The work of others used in its completion has been duly acknowledged; and
- 3. Ethical approval is not required in relation to the writing of this thesis however all appropriate levels of ethical approval have been obtained, where required, for the compendium of published works upon which this thesis relies. The details of any ethical approval required is set out in each of the individual published works (APPENDIX THREE).

AUTHORSHIP

In accordance with the University of Salford regulations, full details of the authorship of each of the published works **(Table 3)** is set out in **APPENDIX ONE.**

Paper	Title	Conception and design	Data collection	Data analysis and/or interpretation	Drafting the paper	Critical revision of draft paper	Final approval of paper
			Core publications	•	·	·	·
(1)	Physical punishment of children: time to end the defence of reasonable chastisement in the UK, USA and Australia	Ø	Ø		Ø	Ø	
(2)	Mandatory Reporting of Female Genital Mutilation in Children in the UK	Ø	Ø			Ø	Ø
(3)	Not Just a Thought	Ø	Ø			Ø	Ø
(4)	Outcomes from the Children and Young People's Advocacy House Consultation Event – MediaCityUK	Ø	Ø			Ø	
(5)	Defining significant childhood illness and injury in the Emergency Department – a consensus of UK and Ireland expert opinion					Ø	Ø
(6)	Diagnostic accuracy of PAT-POPS and ManChEWS for admissions of children from the emergency department	Ø		Ø		Ø	Ø
(7)	Refining and testing the diagnostic accuracy of an assessment tool (PAT-POPS) to predict admission and discharge of children and young people who attend an emergency department: protocol for an observational study	Ø	N/A	N/A		Ø	Ø
		Sup	plementary publication	ons			·
(8)	Life on the tracks	Ø			Ø	Ø	
(9)	From sick kids to SicKids!	Ø	Ø		Ø	Ø	Ø
(10)	Failure to evaluate introduction of female genital mutilation mandatory reporting	Ø	Ø	Ø	Ø	Ø	
(11)	Living on a Railway Line: Turning the tide of child abuse and exploitation in the UK and overseas: international lessons and evidence-based recommendations	Ø	Ø		Ø	Ø	Ø
(12)	Review of the efficacy of rectal paraldehyde in the management of acute and prolonged tonic-clonic convulsions						Ø

ABBREVIATIONS

Table 4: Abbreviations

Abbreviation	Explanation
A&E	Accident and Emergency Department
BMA	British Medical Association
CI	Confidence Interval
CPP	Child Protection Plan
CPR	Child Protection Register (Wales)
CRC	Convention on the Rights of the Child
CRT	Capillary refill time
CSE	Child sexual exploitation
DH	Department of Health
CV	Curriculum vitae
DHSC	Department of Health and Social Care
DKA	Diabetic ketoacidosis
DV	Domestic violence (synonymous with IPV)
ECHR	European Convention on Human Rights
ED	Emergency Department (synonymous with A&E)
FCO	Foreign and Commonwealth Office
FGM	Female Genital Mutilation
GAPRUKI	General and Adolescent Paediatric Research in the UK and Ireland
GCS	Glasgow Coma Scale
GMC	General Medical Council
НМ	Her Majesty's
HRC	Human Rights Convention
ICP	Intracranial pressure
IPV	Inter-partner violence (synonymous with DV)
ManChEWS	Manchester Children's Early Warning System
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
NIHR	National Institute for Health Research

Table 4: (continued)

Abbreviation	Explanation
PAT	The Pennine Acute Hospitals NHS Trust
PED	Paediatric Emergency Department
PEM	Paediatric Emergency Medicine
PERUKI	Paediatric Emergency Research in the UK and Ireland
PhD	Doctor of Philosophy
POPS	Paediatric Observation Priority Score
PPI	Patient and Public Involvement
RCPCH	Royal College of Paediatrics and Child Health
REC	Research Ethics Committee
RfPB	Research for Patient Benefit
ROC	Receiver Operating Characteristics
SD	Standard Deviation
SVC	Superior vena cava
SVT	Supraventricular tachycardia
UCC	Urgent Care Centre
UK	United Kingdom
UN	United Nations
UNICEF	United Nations International Children's Emergency Fund
USA	United States of America
VF	Ventricular fibrillation
VP	Ventricular-peritoneal
VT	Ventricular tachycardia
WCC	White cell count
WCMT	Winston Churchill Memorial Trust
WHO	World Health Organisation

ABSTRACT

This is the thesis component of a Doctor of Philosophy (PhD) by Published Works at the University of Salford, United Kingdom (UK). The overall submission is a portfolio of seven published works supported by five associated publications and a critical appraisal focusing on the contribution that child-rights based legislation, children's advocacy and research into child health topics can collectively play in improving the health and wellbeing of children and young people in the UK and globally. The published works are listed and referenced within this thesis but not contained within it. All the published works referenced within this thesis are linked to from the University of Salford Institutional Repository (USIR) system under author, "Rowland, Professor Andrew G"³.

Legislation and Regulations introduced by the Parliaments, together with common law, sets out what is lawful and unlawful in the UK; children's rights need to be promoted and protected to give the best possible present and future to young people; and child health can only be improved to the maximum potential with optimal overarching child welfare. It is only when the laws in a society properly protect children and young people, there is advocacy on a micro- and macro- basis by healthcare professionals and members of the community, and when there is a focus on child-health a micro- and macro-level, that the health and wellbeing of children and young people will be optimised.

Improving the lives of children and young people in the UK and globally requires a coordinated focus on innovations in three inextricably linked areas: child rights law, children's advocacy and child health. With a clinical, community and research focus on these three areas, truly child-safe communities can be created in which children and young people can develop and flourish happily, healthily and safe from harm.

³ <u>https://usir.salford.ac.uk/view/authors/58020.html</u>

1: INTRODUCTION TO THE THESIS

AIM

The aim of this thesis is to review the contribution that appropriate legislation protecting child rights, advocating for children and young people, and pragmatic (based on practical considerations rather than theoretical ones) **(13)** child health research (using early warning scores in children's emergency medicine as a specific example) can have to improving the health and wellbeing of children and young people both in the UK and globally.

Additionally, this thesis is designed to explain how healthcare professionals being involved in the following three inter-linked areas can have the most beneficial impact on improving the health and wellbeing of children and young people:

- Creating legislation which properly protects the rights of children and young people;
- 2. Children's advocacy; and
- 3. Pragmatic child health research.

OBJECTIVES

There are three overall objectives to this critical review. It sets out the wider disciplinary perspectives surrounding the published works which form the core part of this thesis, describing the context in which those works have been published. It explains the contribution to knowledge that these published works have brought both at a micro-level (in terms of the individual contribution of each paper to new knowledge) and a macro-level looking at the collective contribution to knowledge across all the works. It also provides critical appraisal of the core published works, upon which this thesis is based.

2: BACKGROUND (WIDER DISCIPLINARY PERSPECTIVES)

INTRODUCTION

In this section of the thesis the wider disciplinary perspectives of the theme of my thesis (child-protective legislation, children's advocacy, and improving child health through research) will be explored, explaining the relevant background context and published works which are relevant to these three aspects insofar as they relate to the core published works described in this thesis.

CHILDREN'S ADVOCACY

One definition of advocacy is the "*public support for or recognition of a particular cause or policy*" **(14)** however I think this goes further than simply publicly supporting or recognising an issue. I believe that true advocacy involves promoting, at every possible opportunity, that particular cause (in this case the rights of children) and doing everything possible to facilitate those people whom this cause involves being heard by decision-makers. That belief is supported by the results of the consultation with children and young people about the possible creation of an Advocacy House pilot in the North West of England **(4)**.

While much of the international published material surrounding children's advocacy relies on a child rights based approach. Cohen et al argue that this approach has limitations that impede progress in advancing children's wellbeing as such approaches have, in the USA at least, failed to correct inequities across the country as far as children's access to services are concerned. It is suggested that other approaches are needed to advance children's wellbeing **(15)**. That suggestion is consistent with the theme that is developed in this

4

thesis which is that to truly have the best chance of improving outcomes for children and young people they need a focus on a combination of advocacy (at a macro- and micro-level), improvements in child health (at an individual and societal level) and appropriate legislation in place that properly protects and promotes their rights.

The child advocacy model brings together various sectors to create an integrated, multi-disciplinary response which is client centred. Shaffer et al argue sustainable funding investment in child advocacy centres should be a priority for all levels of government **(16)** which is also consistent with the ultimate aim from the work stemming from the advocacy house consultation **(4)**.

Looking at international aspects of children's advocacy there are a wide variety of types of child advocacy centres in the USA **(11)** and further research is required to understand how these differences affect outcomes for children and young people **(17)**. Reviews have attempted to evaluate the effectiveness of the child advocacy centre model in the USA, uncovering evidence that whilst the criminal justice outcomes of the model have been well studied, there is a lack of research on the effect of the model per se on outcomes for children and families **(18)**. Incorporating research into a child advocacy centre model is needed to evaluate centre-specific outcomes **(19)**.

Health care professionals and organisations have numerous opportunities to cultivate children's participation rights and in doing so improve health care delivery and outcomes. It is therefore important for healthcare providers to

5

develop structures and processes to ensure opportunities for children to participate beginning with the design of such opportunities **(20)**.

Involving children in decision making and development promotes their rights and responsibilities; this can make a positive difference for children locally, and globally **(21)**. However, despite the legal recognition of children's rights to participation, and also the benefits that children experience by their involvement, there is evidence that legislation is not always translated into healthcare practice, with a number of factors impacting on the ability of a child to be involved in decisions regarding their medical care for example those set out in **Figure 1 (22)**.

Capacity of the child to be involved in the decisions
Family situation
Sociocultural context
Underlying beliefs of the healthcare provider

Figure 1: Examples of factors that may impact on the ability of a child to be involved in decisions regarding their healthcare

The Royal College of Paediatrics and Child Health (RCPCH) has detailed worrying concerns about the state of the health of children and young people living in the UK **(23)**. The RCPCH notes that while death rates in young people aged 10 to 19 years of age have decreased over time, most of the remaining deaths are avoidable and the rate of decline in mortality rates for this age group is lower than the RCPCH, and most likely society, would wish for children living in the UK. A strong association is noted between deprivation and life-chances and the report **(23)** highlights that children and young people living in deprived areas are more likely to die. The report further identified concern for communication, personal, social and health education, mental health, and poverty as key themes arising from the RCPCH's consultation with UK based children.

The RCPCH noted a need for more effective communication using modern technology to improve the reach and inclusion of children and young people as well as concerns for mental health issues, finances and lifestyle. It is very clear from the RCPCH's work **(23)**, refreshed during 2020, that children and young people want to be listened to and heard, and should be involved in the coproduction, design and development of services aimed at them. These underlying principles of the right to be heard, to participate and to co-design services, underpinned the structure of our advocacy house consultation work keeping it consistent with evidence-based messages originating from the professional body for paediatrics and child health in the UK.

Children's rights to be heard have been acknowledged for decades and the concept of involving children and young people in the design of initiatives is not new. An eight-rung ladder has been proposed as a hierarchy of participation ranging from manipulation and therapy (non-informing) through informing, consultation and placation (degrees of tokenism), to partnership, delegated power and citizen control (degrees of citizen power), although it has been acknowledged that this is an oversimplification and, in the real world, perhaps the ladder of degrees of participation and co-design may have over 100 rungs with different levels of involvement and power **(24)**.

7

Supporting the views of children and parents, alongside other professionals, advocacy can be used to make lasting improvements in child health **(25)** and it is with that emphasis that my work with children and young people, looking at their understanding of advocacy **(4)** and what they would want for the future, has taken place.

CHILD RIGHTS

Human rights in the United Kingdom (UK) developed over the centuries. In 1215 the Magna Carta was sealed **(26)** and was the first document to put into writing the principle that the King and his government were not above the law. It sought to prevent the King from exploiting his power, and placed limits of Royal authority, by establishing law as a power in and of itself. Clauses 39 and 40 – and their talk of free men, lawful judgment and justice – are themes that can be traced through subsequent legislation **(27)** and the protection of human rights, albeit all human rights and not just those enjoyed by males.

In 1679 the Habeas Corpus Act was introduced, and is still in force today, which prohibits unlawful imprisonment. In effect it means 'you may have the body (if legal procedures are satisfied)' – a medieval phrase used to bring a prisoner to a Court, and later used to fight against arbitrary detention by the authorities **(28)**.

By 1948 the Universal Declaration of Human Rights set out the fundamental human rights to be universally protected **(29)**. These rights, in so far as they specifically mention children, include the right to a standard of living adequate to protect the health and wellbeing of the individual and their family, including food,

8

clothing, housing, medical care, necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control. Specific rights are also included for children (for example, Article 25), all of whom are entitled to enjoy the same protection **(Table 5)**.

Table 5: Universal Human Rights

Article	Summary of Human Right
1	All human beings are born free and equal in dignity and rights and should act towards each other with a common interest.
2	Prohibition of discrimination.
3	Right to life, liberty and security.
4	Prohibition of slavery.
5	Prohibition of torture.
6	Right to be recognised as a person wherever in the world the human being resides.
7	All human beings are entitled equally to the protection of the law and are equally required to abide by the law.
8	The right to have alleged violations of rights remedied by a Court.
9	Prohibition of arbitrary arrest, detention or exile.
10	The right to a fair trial.
11	The right to be innocent until proved guilty and the right to be judged by the law in place at the time a crime was committed.
12	The right to privacy, family life and home life and the right to be protected from defamation.
13	The right to freedom of movement and residence.
14	The qualified right to seek and enjoy asylum.
15	The right to a nationality, including to change nationality, and to be protected from arbitrary deprivation of nationality.
16	The right to marry and found a family and the introduction of equal rights between men and women as to marriage, during marriage and at its dissolution.
17	The right to own property alone as well as in association with others and to not be arbitrarily deprived of property.
18	The right to freedom of thought, conscience and religion.
19	The right to freedom of opinion and expression (free speech).
20	The right to freedom of peaceful assembly and association and the prohibition of being compelled to belong to an association.
21	The right to vote in free elections and to be governed by the will of the people.
22	The right to social security and to have realised the necessary economic, social and cultural rights indispensable for the maintenance of dignity and the free development of personality.

Table 5: (continued)

Article	Summary of Human Right
23	The right to paid free choice of employment with just and favourable conditions, including just and favourable remuneration, and protection from unemployment.
	The right to equal pay for equal work and the right to form and join trade unions.
24	The right to rest and leisure, including reasonable limitation of working hours and periodic holidays with pay.
25	The right to a standard of living adequate to protect the health and well-being of the individual and their family, including food, clothing, housing, medical care, necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control.
	Specific rights to protect mothers and children, and for all children to enjoy the same social protection.
26	The right to education and the qualified right to free education.
	The direction that education shall promote understanding, tolerance and friendship.
	The parental right to choose the kind of education that shall be given to their children.
27	The right freely to participate in the cultural life of the community, to enjoy the arts and to share in scientific advancement and its benefits.
	The right to protection of the moral and material interests resulting from any scientific, literary or artistic production authored by the individual.
28	The entitlement to a social and international order in which the rights and freedoms in the Universal Declaration of Human Rights can be fully realized.
29	The declaration that everyone has duties to the community in which alone the free and full development of the individual's personality is possible.
	The declaration that in the exercise of rights and freedoms, the only permissible limitations are those determined by law as being necessary to respect the rights and freedoms of others and to ensure public order, general welfare and morality in a democratic society.
30	The direction that nothing in the Universal Declaration of Human Rights can be used to engage in any activity or to perform any act aimed at the destruction of any of the rights and freedoms set out within it.

In 1950 the European Convention on Human Rights (ECHR) was introduced which specifies the agreed rights and freedoms that should be guaranteed to all people **(30)** of the States which are party to it. Some rights are absolute and cannot be limited or restricted at all; some are limited (so a person may be deprived of this right in certain circumstances, for example when it is necessary to deprive someone of their liberty for the protection of others); and some are qualified and may be interfered with in order to achieve another aim specified in the ECHR **(Table 6)**.

Article	Right or freedom
1	Obligation to respect Human Rights
2	Right to life
3	Prohibition of torture
4	Prohibition of slavery and forced labour
5	Right to liberty and security
6	Right to a fair trial
7	No punishment without law
8	Right to respect for private and family life
9	Freedom of thought, conscience and religion
10	Freedom of expression
11	Freedom of assembly and association
12	Right to marry
13	Right to an effective remedy
14	Prohibition of discrimination
15	Derogation in time of emergency
16	Restrictions on political activities of certain people
17	Prohibition of abuse of rights
18	Limitation on use of restrictions on rights

Table 6: The Articles of Section 1 of the European Convention on HumanRights

A major breakthrough specifically for the protection of the rights of children was the United Nations Convention on the Rights of the Child (UNCRC) 1989, which came into force in the UK in 1992 **(31)**. This also introduced the definition of a child as anyone who has not yet reached their 18th birthday. The UNCRC has 54 articles in total. Articles 1 to 42 are the rights of children in specific circumstances and generally **(Table 7)**. Articles 43 to 54 are about how adults and governments must work together to make sure all children can enjoy all of their rights **(32)**.

The UNCRC defines prerequisites for the optimal survival and development of children and the obligations of others, including individuals, parents, communities and States, to fulfil this right **(33)**. It provides strategies for rights-based approaches to clinical practise and health systems and there is a clear intersection between child rights and paediatric bioethics **(33)**.

It is common ground that not listening to children's views on matters that affect them is wrong and is a breach of their human rights. However, whilst seeking children's views in a tokenistic fashion is wrong, it has been argued that not seeking their input on the basis that it would also be tokenistic is also wrong but arguably not as wrong as not seeking their views at all **(34)**.

Table 7: Articles of the United Nations Convention on the Rights of the Child

1	Area covered by the right Definition of a child
2	Non-discrimination
3	Best interests of the child
4	Implementation of the Convention
5	Parental guidance and a child's evolving capacities
6	Life, survival and development
7	Birth registration, name, nationality, care
8	Protection and preservation of identity
9	Protection from separation from parents
10	Family reunification
11	Protection from abduction and non-return of children
12	Respect for the views of the child
13	Freedom of expression
14	Freedom of thought, belief and religion
15	Freedom of association
	Right to privacy
17	Access to information from the media
	Parental responsibilities and state assistance
	Protection from violence, abuse and neglect
20	Children unable to live with their family
21	Adoption
22	Refugee children
23	Children with a disability
24	Health and health services
25	Review of treatment in care
26	Social security

Table 7: (continued)

Auticle	Amon account by the simble
Article	Area covered by the right
27	Adequate standard of living
28	Right to education
29	Goals of education
30	Children from minority or indigenous groups
31	Leisure play and culture
32	Child labour
33	Drug abuse
34	Sexual exploitation
35	Abduction, sale and trafficking
36	Other forms of exploitation
37	Inhumane treatment and detention
38	War and armed conflicts
39	Recovery from trauma and reintegration
40	Juvenile justice
41	Respect for higher national standards
42	Knowledge of rights

In the UK further rights-based legislation followed the introduction of the UNCRC, including the Human Rights Act (1998) **(35)** and the Equality Act (2010) **(36)**. The UNCRC is the most widely ratified human rights treaty in the world. It has been ratified by all United Nations member states *except* the USA **(37)**. In addition, it has even been accepted by non-state entities, such as the Sudan People's Liberation Army in South Sudan. It is wholly unacceptable that the USA has not ratified this treaty and, clearly, does not value child rights in the same way that other member states do; however, this does link in with the

findings from my research, particularly in relation to protection of children from physical punishment, incorporated into this thesis.

The publications on physical punishment of children (1) and female genital mutilation (2, 10) promote children's rights to health, and rights to be protected by laws that have been fully evaluated. In *Not Just a Thought...* (3) and the Advocacy House consultation (4) over 100 children and young people were engaged with about protecting and promoting their rights, protecting them from exploitation of all forms, including child abuse and neglect, respecting their freedom of thought and freedom of expression and respecting their views as children, all of which are underpinned by key principles in the Universal Declaration of Human Rights (29), the ECHR (30) and the UNCRC (31).

My reports *Living on a Railway Line* (11), *Life on the tracks* (8) and *From sick kids to SicKids!* (9) are focused on my thoughts at the time of their publication about what needed to change in the UK to protect children better from harm. Those publications have a significant focus on child rights, and the legislative changes required in several jurisdictions, and what progress has been made since that time towards implementing the required changes.

Looking critically at how the body of core publications underpinning this thesis fits into the wider context of the development of child rights in the UK and internationally, it is clear that the new knowledge contained within my published works is directly relevant to the wider aspects of child rights, especially in terms of children's advocacy.

LEGISLATION

Introduction

The UK is a common law jurisdiction. What is lawful and unlawful is determined from both statute (legislation in Acts of the relevant Parliament) and law derived from judicial decisions of courts and tribunals ("common law") - with the judgments of the most senior of those courts binding the lower courts. Not all countries have a common law jurisdiction; some, for example, having a civil law jurisdiction in which all laws are set out in statute **(38)**.

Within any country the law is best seen as enforcing what a society is prepared to accept as appropriate conduct. Caution must be exercised when introducing aspirational legislation which may not have the immediate support of a significant number of members of society. However, the situation for children at risk of significant harm is serious enough to warrant legislative change in a number of jurisdictions, including here in the UK.

A society must be careful about passing too many laws that are aspirational in nature and which that same society is not prepared to enforce. Accordingly, if there is to be legislative change, it must be rigorously enforced rather than ignored both by those to whom it is intended to apply and those who are charged with investigating alleged breaches. Any such legislative change must diminish human suffering, increase human equality, and increase the ability of all children to start and continue their lives with equal chances of happiness **(39)**.

In my 2014 publication *Living on a Railway Line* **(11)** I made a number of recommendations for legislative change in the UK including the introduction of mandatory reporting of child abuse and the prohibition of physical punishment of children (the introduction of equal protection for children).

Female Genital Mutilation

The Female Genital Mutilation Act 2003 made this practice illegal in England and Wales **(40)**. It is a form of child abuse and violence against women. Female genital mutilation (FGM) comprises all procedures involving partial or total removal of the external female genitalia for non-medical reasons. The Serious Crime Act 2015 **(41)** amended the Female Genital Mutilation Act 2003 to introduce a mandatory reporting duty. It requires regulated health and social care professionals and teachers in England and Wales (only) to report to the police known cases of Female Genital Mutilation (FGM) in children aged under 18 years of age which they identify in the course of their professional work.

While FGM has been illegal in the UK since 1985, it was only in 2003 that taking children abroad for the purposes of subjecting them to FGM became a criminal offence. It has been estimated that more than 100,000 women and girls aged between 15 and 49 years of age who have had FGM performed on them are living in the UK (42, 43). The study on the mandatory reporting of FGM in children in the UK (2, 10) investigated the number of cases of FGM reported to the police before and following the introduction of mandatory reporting of FGM in October 2015. The aim was to ascertain what impact the legislation had had on the reporting of FGM in England and Wales.

It was found that FGM records are made but not followed up in significant enough numbers for the purpose of reporting, and that there had not been a robust academic evaluation of the law introducing mandatory reporting of FGM. It was concluded that mandatory reporting and recording of FGM are more symbolic than effective, and that there should be national data collection by a central authority led by an FGM Commissioner.

Physical Punishment Of Children

The recommendation in *Living on a Railway Line* for the introduction of legislative change to prohibit physical punishment of children in all settings (in effect to remove the defence of reasonable chastisement) was built upon in a comparative context by investigating perspectives from the UK, the USA and Australia **(1)**.

Physical punishment of children, of course, violates their human rights, being contrary to the Universal Declaration of Human Rights (29), the ECHR (30) and the UNCRC (31). It remains deeply worrying that the USA has neither ratified this child-protective treaty nor has it adopted the two optional protocols (44, 45). Despite physical punishment of children being contrary to their child (and indeed human) rights, at the time of the publication in 2017 in the UK parents were not explicitly prohibited from physically punishing their children, for example smacking them.

Section 58 of the Children Act 2004 **(46)** limited the use of the defence of reasonable punishment so that parents and those acting *in loco parentis* who cause physical injury to their children can no longer use the "reasonable

punishment" defence where they are charged with assaults occasioning cruelty, actual or grievous bodily harm. The defence of "reasonable punishment" is available only to parents or others acting in loco parentis, provided they are not expressly prohibited from using physical punishment (for example in schools) when the charge would be one of common assault. Physical punishment is prohibited in all maintained and full-time independent schools, in children's homes, in local authority foster homes and early years provision.

There is a clear inconsistency between permitting physical punishment of children in the UK and Article 19 of the UNCRC **(31)** as any physical punishment of a child constitutes physical violence, and in the UK this should be considered as an offence of at least common assault. Common assault is committed when a person assaults another person or commits a battery. An assault is committed when a person intentionally or recklessly causes another to apprehend the immediate infliction of unlawful force. A battery is committed when a person intentionally and recklessly applies unlawful force to another **(47)**. In essence these definitions mean that an "assault" can be committed without physical contact between the perpetrator and victim (and the victim merely perceiving that immediate unlawful physical contact is about to be inflicted on them by the perpetrator) and a "battery" is the actual application (infliction) of unlawful force to the victim by the perpetrator.

Complete removal of the defence of reasonable punishment in the UK, under Section 58 of the Children Act 2004, has been recommended by a number of other organisations including the Equality and Human Rights Commission, all four Children's Commissioners, the Commission on the Family and Wellbeing of

Children and the UK Parliamentary Joint Committee on Human Rights. No defence of reasonableness exists in relation to adult victims – only children.

Since the publication of the 2017 study on physical punishment of children it has been possible academically to lobby the children's commissioners in the UK as well as key parliamentarians to see if there is an appetite for legislative change in the UK. New legislation, to the development of which the study and follow-up communications contributed, has now been introduced in Scotland (48) and Wales (49) to give to children the same protection from assault as that enjoyed by adults. Northern Ireland and England remain devoid of the legal protections that children deserve and are entitled to, although those jurisdictions might be convinced to undertake the necessary public consultations and legislative changes in the future.

CHILD HEALTH

The State Of Child Health In The UK

Bringing together available data across the UK, the RCPCH launched a landmark report providing a snapshot of the physical and mental health of infants, children and young people **(50)**. This 2020 report provides the latest data from the RCPCH's 2017 indicators, alongside evidence for new indicators including looked after children, mental health, youth violence, young carers and the child health workforce. Alongside this, the RCPCH spoke to 2000 children and young people to find out what made them feel healthy, happy and well.

The RCPCH reports in its 2020 State of Child Health publication (Figure 2) (50) that although, for example, infant mortality is decreasing in Wales, Scotland and Northern Ireland it remains essentially unchanged from 2017 in England. Worryingly, adolescent mortality in Scotland rose between 2017and 2020 with increases in suicide rates in those aged 15 to 24 years old across all four nations of the UK.

During this period there has been continued improvement in blood glucose control among children and young people with Type 1 diabetes across England and Wales, and there have been increases in the completion of key health checks for those with diabetes (51). In England, rates of emergency admission to hospital for epilepsy have fallen among those living in the most deprived areas, across all age groups (52).

Highest rate or percentage of the four UK nations

Lowest rate or percentage of the four UK nations

	England	Wales	Scotland	Northern Ireland				
Mortality			ooodaana					
Infant mortality rate per 1,000 live births	Unchanged 3.9 to 3.9	Decreasing 3.7 to 3.5	Decreasing 3.6 to 3.2	Decreasing 4.8 to 4.2				
Child mortality rate per 100,000 children aged 1-9	Decreasing 11.9 to 9.9		Increasing 9.3 to 9.7	Decreasing 12.5 to 9.7				
Adolescent mortality rate per 100,000 children age 10-19	Decreasing 17.1 to 17.0		Increasing 19.5 to 24.6	Decreasing 24.4 to 20.5				
Maternal and perinatal health								
Smoking during pregnancy England and Wales: % at time of delivery. Scotland and Northern Ireland: % at first booking	Decreasing 11.7% to 10.6%*	16.0%**	Decreasing 18.3% to 14.6%*	Decreasing 14.5% to 13.2%*				
Breastfeeding - % exclusively breastfeeding. England, Scotland & Northern Ireland: at 6-8 week review. Wales: at 6 week review	Decreasing 30.1% to 29.6%	Increasing 19.7% to 20.8%	Increasing 27.2% to 30.7%	Increasing 22.8% to 23.9%				
Prevention of ill health								
Immunisations - 5-in-1 vaccination coverage at 12 months	Decreasing 94.2% to 92.1%	Decreasing 96.6% to 95.4%	Decreasing 97.4% to 95.9%	Decreasing 97.3% to 94.8%				
Immunisations - % of MMR vaccination coverage (second dose) at 5 years	Decreasing 88.6% to 86.4%	Decreasing 93.1% to 92.2%	Decreasing 93.4% to 91.2%	Decreasing 93.0% to 91.8%				
Healthy Weight – % of 4-5 year olds recorded as overweight or obese	Increasing 21.9% to 22.6%	Increasing 26.1% to 26.4%	Increasing 21.8% to 22.4%	Increasing 25.1% to 26.1%				
Oral health – rate of tooth extraction due to tooth decay England & Scotland: per 1,000 children aged 0-5 Wales: per 1,000 children aged 0-2	Decreasing 3.6 to 2.8	Decreasing 2.8 to 1.7*	Decreasing 3.6 to 2.3	No data				
Injury prevention								
Accidental injury – rate of hospital admission due to non intentional injury per 1,000 children aged 0-4	Decreasing 13.9 to 12.8	Decreasing 19.1 to 16.1	Decreasing 11.7 to 10.7	No data				
Road traffic accidents – rate of total road traffic injuries per 1,000 young people aged 17-19	Decreasing 4.0 to 3.4	Decreasing 4.9 to 3.4	Decreasing 3.6 to 2.8	No data				
Youth violence – incidence of injury by sharp object per 100,000 young people aged 15-19	Increasing 36.5 to 38.3	Unchanged 33.8 to 33.8	Decreasing 40.7 to 38.5	Decreasing 39.8 to 38.2				
Health behaviours								
Young people smoking - England, Wales & Scotland: % of 15 year olds reporting as regularly smoking (within the previous week) Northern Ireland: % 11- 16 year olds smoking within the last week	Decreasing 7.7% to 5.1%	Increasing 8.0% to 9.0%	Decreasing 8.6% to 7.0%	Decreasing 4.2% to 4.1%*				
Young people drinking - England, Wales & Scotland: % 15 year olds reporting being drunk 2 or more times. Northern Ireland: % 11-16 year olds being drunk 2-3 times	Decreasing 28.0% to 26.0%	Decreasing 31.0% to 18.0%*	Decreasing 32.5% to 31.5%	Increasing 11.0% to 12.6%*				
Young people consuming drugs - % of 15 year olds reporting ever having used cannabis	Increasing 19.0% to 21.0%	Increasing 17.5% to 21.0%	Decreasing 17.0% to 16.5%	No data				

Figure 2: Key findings from the RCPCH State of Child Health 2020 report

The rate of conceptions among those under 18 years of age has decreased over the past decade in England, Scotland and Wales – with trends in livebirths to teenage mothers in Northern Ireland (the closest alternative indicator available) reflecting a similar picture **(53)**. Oral health in young children continues to improve, particularly in Scotland and Wales **(54)**. However, despite these improvements it remains the case that progress in reducing child and adolescent mortality has stalled recently **(55)**. The lack of progress in infant mortality in England from 2013 to 2018 (with a slight rise seen in 2017) is a worrying finding **(56)**.

Efforts to reduce smoking during pregnancy have stalled and the proportion of women in Scotland who reported smoking at the first health visitor review has increased (57). Tackling obesity remains problematic and continues to be a challenge with over a third of children and young people aged 10 or 11 years of age in England being overweight or obese (58). Vaccination rates have fallen universally, and England and Wales have recently lost their World Health Organization measles-free status (59).

In the light of all this, when improvements in child health have not been universal over recent years, and in some areas there have been deteriorations in indicators, what is it that healthcare professionals can do? The RCPCH recommends five key steps for healthcare professionals to do their part to tackle the issues raised **(60)**:

- 1. Make every contact count;
- Signpost disadvantaged children, young people and their families to sources of support;

- 3. Advocate for local children, young people and their families;
- 4. Take an active role in supporting child health research and data collection; and
- 5. Make child health a joyful place to work.

It is clear that all of the above principles underpin the theme in this thesis. I believe the evidence set out in my published works, in conjunction with the appraisal of those works in this thesis, goes further than this. It explains how professionals and communities could act differently to make the best possible improvements in child health at an individual and societal level. They must play their part in ensuring that national legislation and policy properly protect the interests of children and young people in addition to advocating for children and young people and promoting their health at a micro- and macro-level. It is that focus on child health research that is addressed now, reviewing critically the wider disciplinary aspects of the child health research that is relevant to this thesis.

Early Warning Scores And Systems In Children's Emergency Medicine

Health professionals make judgements on whether children attending emergency departments need to be admitted to hospital or can safely be sent home. Since at least 2006 it has been recommended that early identification systems should be used to recognise children developing critical illness (61). Many paediatric early warning scores use track and trigger systems, relying on repeated observations over time to identify early indicators of deterioration, and they are intended for use with children who are admitted to hospital (62-69). They are intended to predict which children are likely to deteriorate. This is very different from needing a score in the emergency department to help determine which children should be admitted to hospital and which could be discharged **(70)**.

No universally validated children's early warning score or system exists to predict likelihood of admission from the emergency department. The NHS Institute paediatric early warning score is a valid tool with good diagnostic accuracy in recognising children at risk of serious illness and life-threatening deterioration. However, further work is needed to determine whether other subjective measures have any value in paediatric early warning scoring tools (71).

The Pennine Acute Hospitals NHS Trust (PAT) Paediatric Observation Priority Score (POPS) is a new children's early warning score designed for use in emergency departments **(72)**. It combines physiological measurements and clinical observation into an aggregate scoring system. Preliminary work found PAT-POPS to be a more accurate predictor of admission risk than the Manchester Children's Early Warning System (ManChEWS) – a track and trigger system devised for inpatients which has been shown to over-trigger **(64)**. This may lead healthcare professionals to become immune to the score (effectively not responding to the intended trigger).

Research was undertaken to compare the ability of ManChEWS and PAT-POPS to predict admission from the children's emergency department. This concluded that replacing ManChEWS with PAT-POPS would appear to be

clinically appropriate in a children's emergency department – however this requires validation in a multi-centre study **(6)**.

Improving the performance of PAT-POPS could have a number of benefits in urgent and emergency care settings including identifying those children and young people that need to be admitted and are more likely to be sicker, compared with those who can be discharged. Such earlier identification will allow the right children to be prioritised for urgent, senior medical care. Additionally, improving the performance of PAT-POPS ought also be able to increase identification of those children and young people who are well enough to be referred back to primary care or self-care at home, thereby reducing the number of children who are in hospital when they ought to be at home in their normal social and family situation **(7)**.

Defining Significant Childhood Illness And Injury In The Emergency Department

The need to verify whether scoring systems are able accurately to predict severe illness or injury in the emergency department has been highlighted as one of the top research priorities for paediatric emergency medicine in the UK and Ireland (73). For that reason there is a need to define significant childhood illness and injury in the emergency department to facilitate quality research in this area (5).

No paediatric early warning score has yet demonstrated an impact on reducing mortality for hospitalised children **(74-76)**. Studies have shown varying accuracy between different scoring systems in identifying the sick child or the child who

requires hospital admission (77-80) and in one study the authors compiled their own list of significant illness definitions, which they then used as a benchmark to assess PEWS performance (78). It is, however, unknown whether the list used is reflective of a broader group of expert opinion.

To facilitate future paediatric early warning score research in the emergency department a study was designed to create a benchmark list defining the significant acute paediatric conditions that warrant an acute admission to hospital from the emergency department **(5)**. Through consensus opinion, a list of 154 paediatric illnesses and injuries warranting acute admission to hospital from the emergency department has been established. This robust list of conditions can now be used to investigate the performance of paediatric early warning scores and other child patient safety initiatives in the UK and Ireland and, potentially, other countries with similar healthcare settings.

Efficacy Of Rectal Paraldehyde: An Example Of Clinical Child Health Research

One example of a condition which certainly requires admission of a child to hospital is status epilepticus (acute, prolonged seizures). In the UK the latest guidelines for the treatment of status epilepticus involve benzodiazepine administration initially, followed by either phenytoin or phenobarbitone if there is no resolution of the seizure (and, whilst this is being prepared, administration of rectal paraldehyde) followed by a rapid sequence induction of anaesthesia if the seizure continues (Figure 3) (81).

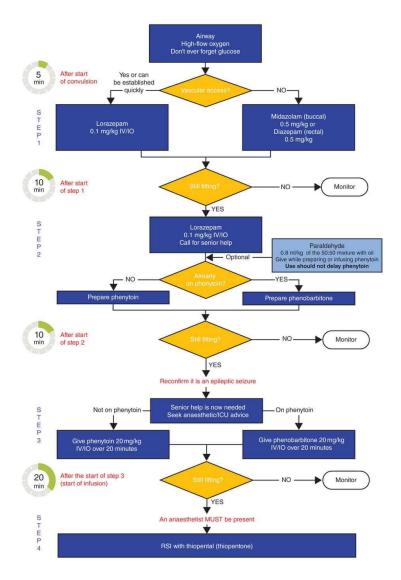


Figure 3: ALSG algorithm for the management of status epilepticus in children

Although paraldehyde has been used as an anti-convulsant for over 50 years, there has not always been agreement over which other anti-convulsant drugs should feature in the guideline for the management of status epilepticus in children **(82)**.

Despite the accepted role of paraldehyde in the management of tonic-clonic convulsions, prior to the publication of the study reviewing the efficacy of rectal

paraldehyde there were very limited published data on its effectiveness and safety **(83)**. These had focused primarily on its intramuscular route of administration **(84)**. Toxicity has been reported rarely with the use of paraldehyde as an anticonvulsant following intravenous **(85, 86)** and intramuscular administration **(87)**.

Given the paucity of evidence surrounding the safety of paraldehyde in children our study exploring the efficacy of rectal paraldehyde set out to establish the effectiveness and safety of rectal paraldehyde in the management of prolonged tonic-clonic convulsions in children.

SUMMARY

Involving children in decision making and policy development promotes their rights and responsibilities. This can make a positive difference to children locally and globally (21). By supporting the views of children and parents alongside those of other professionals, advocacy can be used to make lasting improvements in child health (25). It is with that emphasis that my work with children and young people to investigate their understanding of advocacy (4) and what they would want for the future has taken place.

The UNCRC defines prerequisites for the optimal survival and development of children, together with the obligations of others, including individuals, parents, communities and states, to fulfil this right **(33)**. It provides strategies for rights-based approaches to clinical practise and health systems, and there is a clear intersection between child rights and paediatric bioethics **(33)**. It is common

ground that not listening to children's views on matters that affect them is wrong and is a breach of their human rights.

Mandatory reporting and recording of FGM has been found to be more symbolic than effective, and national data collection should be undertaken by a central authority led by an FGM Commissioner. Review of the legislation supporting the protection of children in the UK and globally shows clear inconsistency between permitting physical punishment of children in the UK and Article 19 of the UNCRC **(31)**. New legislation, the development of which was supported by our research paper and follow-up communications, has now been introduced in Scotland **(48)** and Wales **(49)** to give the same protection from assault to children as is enjoyed by adults, although Northern Ireland and England remain devoid of the legal protections that children deserve and are entitled to.

Given that improvements in child health have not been universal over recent years, and in some cases there has been a deterioration in indicators, there is a role for healthcare professionals to do their part to tackle the issues raised by the RCPCH as being detrimental to child health **(60)**. Further work is also needed to determine which elements ought to exist in children's early warning scores and systems to be of validated use in emergency care settings **(71)**. That work has been undertaken in a study, in which I was principal investigator, funded by the National Institute for Health Research (NIHR) in the UK **(7)**.

Additionally, through consensus opinion a list of 154 paediatric illnesses and injuries warranting acute admission to hospital from the emergency department has been established. This robust list of conditions can now be used to

investigate the performance of paediatric early warning scores and other child patient safety initiatives in the UK and Ireland and, potentially, other countries with similar healthcare settings.

Using status epilepticus in children as one example of how healthcare professionals can conduct research to improve the health of children and young people, given the paucity of evidence surrounding the safety of paraldehyde in children our study looking at the efficacy of rectal paraldehyde set out to collect data on the effectiveness and safety of rectal paraldehyde in the management of prolonged tonic-clonic convulsions in children.

Overall it is clear that there must be legislation underpinning child rights, with proper protection of all of a child's rights in accordance with the UNCRC, together with advocacy by professionals for children at a local and global level, and a focus of those professionals on child health research if we are to have the best possible chance of improving the health and wellbeing of children and young people both in the UK and globally.

3: METHOD

INTRODUCTION

Chapter 4 details the critical appraisal of the research methods reported in the core publications that support this thesis. In this chapter 3 the emphasis is on detailed presentation of the research methods employed with indications of how these led to robust studies and impactful evidence. The methods are described in detail for each of the core published works and, only where relevant to the conclusions of this thesis, the methods of the accompanying (supporting) published works are described.

RESEARCH METHODS

There are said to be three primary research methods (88): qualitative (89-94), quantitative (93-95) and mixed methods (93, 96, 97). It has been proposed that the distinction between qualitative and quantitative research is abstract and general, and it has been suggested it may be preferable not to conceptualise research approaches at such abstract levels (98). Nonetheless, the methodology of the works underpinning this thesis can be categorised. Methods used in the published works supporting this thesis include qualitative methods (core paper 3, core report 4, supplementary report 8, supplementary published letter 10 and supplementary report 11), quantitative methods (core paper 2, core papers 5-7 and supplementary paper 12), mixed methods (core paper 1 and supplementary report 9), ethnography (supplementary report 9 and supplementary report 11) (99-101), participatory action research (core report 3 and core report 4) (102-107) and pragmatic paradigm (supplementary report 9 and supplementary report 11) (108) (Table 8).

Label	Theme	Published work	Methodology
Core paper (1)	Law	Physical punishment of children: time to end the defence of reasonable chastisement in the UK, USA and Australia	Mixed methods Documentary and content analysis
Core paper (2)	Law	Mandatory Reporting of Female Genital Mutilation in Children in the UK	Quantitative secondary analysis
Core report (3)	Advocacy	Not Just a Thought	Qualitative Participatory action research
Core report (4)	Advocacy	Outcomes from the Children and Young People's Advocacy House Consultation Event – MediaCityUK	Qualitative Participatory action research
Core paper (5)	Health	Defining significant childhood illness and injury in the Emergency Department – a consensus of UK and Ireland expert opinion	Quantitative Prospective descriptive using Delphi
Core paper (6)	Health	Diagnostic accuracy of PAT-POPS and ManChEWS for admissions of children from the emergency department	Quantitative Prospective observational
Core paper (7)	Health	Refining and testing the diagnostic accuracy of an assessment tool (PAT- POPS) to predict admission and discharge of children and young people who attend an emergency department: protocol for an observational study	Quantitative Prospective observational cohort study
Supplementary report (8)	Law Health Advocacy	Life on the tracks	Qualitative impact analysis
Supplementary report (9)	Health Advocacy	From sick kids to SicKids!	Pragmatic mixed methods with an emphasis on ethnography
Supplementary published letter (10)	Law	Failure to evaluate introduction of female genital mutilation mandatory reporting	Qualitative secondary analysis
Supplementary report (11)	Law Health Advocacy	Living on a Railway Line: Turning the tide of child abuse and exploitation in the UK and overseas: international lessons and evidence-based recommendations	Pragmatic mixed methods with an emphasis on ethnography
Supplementary Health paper (12)		Review of the efficacy of rectal paraldehyde in the management of acute and prolonged tonic-clonic convulsions	Quantitative Prospective descriptive study using audit techniques

Table 8: Methods used in the portfolio of published works

CORE PUBLICATIONS

Core Paper (1)

This study employed mixed methods with documentary and content analysis involving two main components. First, a literature review was conducted to establish the effects of physical punishment of children, the steps that countries around the world have taken to protect children from corporal punishment, beginning with the case of Mary Ellen Wilson **(109, 110)** in the USA, and child abuse statistics from the UK, USA and Australia. This part of the research was retrospective and descriptive of existing qualitative and mixed data. Second, a legislative review was completed of international law and the specific position in the UK, USA and Australia regarding whether, and if so to what extent, physical punishment of children is either permitted or prohibited. This part of the research was retrospective and statistically analytical. Analysis of this data by a multi-disciplinary team involving a social worker, lawyer and medically-qualified doctor, enabled key recommendations to be made for legislative change in the UK, Australia and the USA.

The mixed methods chosen for this study enabled a qualitative analysis of international legislative comparisons as well a quantitative approach to the analysis of child abuse statistics available in the UK, the USA and Australia. In future work it will be useful and important to undertake further primary research to consider the views of children and young people regarding equal protection and physical punishment, especially now that there has been legislative change in Scotland **(48)** and Wales **(111)**.

Both quantitative and qualitative research uses empirical methods to decipher legal processes. They differ, however, in how they go about this deciphering. Quantitative research is usually designed to test hypotheses or to establish causal links, and statistical analysis will produce valid results only if the data are of high quality and recognised as being categorical or scale data in nature. Qualitative research often attempts to answer a question, often in order to identify worthwhile hypothesis for statistical testing. Issues to be considered when assessing qualitative legal research designs include whether the case is uniquely appropriate for the study in question, whether the research question can be answered with the available data, whether there is a broader phenomenon that is being studied through a particular case, and whether the study will advance legal theory regarding the particular area being studied. A high-quality study will produce rich and complex (multi-faceted) knowledge of particular phenomena **(112)**.

The case-based method of establishing the law through analysis of precedent (in a common law jurisdiction) is a form of qualitative research using documents as source material. In qualitative legal research, the data are usually collected through three main methods, used singly or in combination: direct observation, in-depth interviews and analysis of documents **(89)** including primary legislation (statute) and case law. The data may include notes made by the researcher that provide a detailed description of what, where, and how people did what they did, their interactions or their processes, or a description of the researcher's observations and reactions to text-based sources, sounds, video or images. Data may also be in the form of a transcript or verbatim quotes of what was said

by the research participants and the researcher, or what was written in the text sources being examined. Consequently, data may be derived from the research participants directly (in the form of quotes) or from texts and images, or via the researcher in the form of personal reaction to or understanding of what was said or written **(89)**.

There are five basic aspects of designing a qualitative empirical legal research study once the research question has been decided **(89)**:

- The methodology that is the most appropriate to answer the question within any constraints such as limited access to data or ethical considerations must be determined. For example, this might require consideration of whether a case-study method, surveys and interviews, participant observation and ethnography, documentary analysis, or a combination of such methods is likely to answer the question most effectively.
- Selection of the research subjects or documents and how many to select, in keeping with the data collection must be considered.
- How the data are to be analysed needs to be decided, for example whether a grounded-theory method, content analysis, discourse analysis, thematic coding, historical or linguistic analysis, or statistical analysis will be used.
- Appropriate ethics approval must be gained so as to do no harm to participants (non-maleficence) and, if possible to do some good (beneficence) (113).

 Taking into account whether the researcher is working alone or in a team may have an impact on various aspects of the research design.

Qualitative methods can be used for exploratory research (research that is designed to examine whether an issue, situation or problem exists and if so to define it). Quantitative research methods can be used for explanatory research (research designed to determine why or how an issue, situation or problem is as it is). However, both types may be used for descriptive studies (research designed to describe an issue, situation, problem or set of attitudes) **(89)**.

Qualitative methods of legal research may be particularly appropriate for analysing institutions that produce law and/or quasi-legal agreements and policies (for example a government, the United Nations or the European Union) (112). It is for this reason that although a mixed methods descriptive study design was employed it majored on qualitative legal research.

Core Paper (2)

This study involved quantitative secondary analysis of data obtained using the provisions set out in the Freedom of Information Act 2000 **(114)**. Reporting of cases of female genital mutilation (FGM) to the 45 UK police authorities was investigated via email requests to the police authorities requesting data on:

 How many cases of FGM were reported to each police force each month between 31 October 2015 and 21 February 2016, stratified, if possible, by age of alleged victim and occupation of person making the report;

- How many cases of FGM were reported to each police force each month between 31 October 2014 and 31 October 2015, stratified, if possible, by age of alleged victim and occupation of person making the report; and
- The age-breakdown, sex-breakdown and total population of each police force area in 2014 and 2015.

Similar requests were also sent to NHS England (115), the Home Office (116), the then Health and Social Care Information Centre (117) (now NHS Digital (118)) and the then Department of Health (119) (now Department of Health and Social Care), asking how many cases of FGM had been reported to the organisation within the given timescales. The Office for National Statistics (120) was asked to supply data on the age-breakdown, sex-breakdown and total population of each local authority area. Quantitative data received were analysed using Microsoft Excel and the cited reasons for any refusals to supply data were analysed by thematic analysis (121).

The UK Freedom of Information Act 2000 was enacted in 2000 and came into full force in 2005 (114). The Act gives access to a plethora of data and the potential of using such data is only as limited as the questions posed by researchers (122), however while its use to obtain data may be financially beneficial for those performing research, questions have been raised about the collective cost (122, 123) to the public sector in the UK associated with collation and release of the information requested. One of the major limitations of using this method of data acquisition is that there are provisions within the legislation to refuse a request including those listed below.

- Cost exemption (processing the request would cost more than £600 for Parliament, the armed forces and central government or £450 for other bodies)
- Vexatious requests (it is the *request* that may be considered vexatious not the *requester*)
- Sensitive personal information requested is protected under the Data Protection Act 2018
- Exemptions set out in Part II of the Freedom of Information Act 2000 (absolute, to which the public interest test does not apply, and nonabsolute, to which the public interest test does apply), inter alia matters pertaining to law enforcement, national security, prejudicing international relations, prejudicing defence of the UK, endangering health and safety).

Whilst internal and external (to the Office of the Information Commissioner) appeal mechanisms exist within the Act, exhausting those appeal mechanisms may take considerable time (potentially in excess of six months if an individual wishes to complain to the Office of the Information Commissioner about an organisation's handling of a request), and this may limit the utility of using such legislation to obtain information for research purposes.

Nonetheless, the Act is a powerful tool for researchers (124-126), and greater use should be made of it (122) as it enables researchers to obtain information from public bodies. This method of data acquisition was chosen as an exploratory method to ascertain if it would be possible to analyse the data that was released. The success of this method has enabled further research to take

place using the same method principles to evaluate the introduction of FGM protection orders (127).

Core Paper (3)

This qualitative participatory action research study began with a theatre play called *Somebody's sister, Somebody's daughter* **(128)** and a discussion of the issues that it raised with children, young people, parents and practitioners. The production is designed to tackle the sexual exploitation of young people, with emphasis on providing a greater understanding and awareness of street grooming, social media vulnerability, online threats and 'sexting'. *Somebody's Sister, Somebody's Daughter* dramatizes the dangers and the complex issues involved in child sexual exploitation (CSE). Aimed at Year 10 students and upwards, and available also for professionals, the play is supported by specially written pre- and post-performance lesson outlines. Every performance is followed by a hot-seating session in which the actors come back in character so that audiences can question their actions and behaviour **(128)**.

The purposes of the theatre play and its related resources are:

- To inform and warn potential victims, and to encourage self-protective behaviour;
- To provoke potential abusers into reconsidering their thinking;
- To stimulate general debate and raise awareness around the subject;
- To be a resource and training tool for workers;
- To lead local authority prevention strategies with monitoring & evaluation tools;

- To signpost key local and national CSE services and support;
- To increase vigilance and resilience against CSE; and
- To encourage and empower victims of CSE to seek help and support.

An exploratory, participatory phase of research was begun. Following practitioners, children and young people watching the play, consultation events, involving focus groups **(129-133)**, were held with multidisciplinary practitioners in Manchester and Dorset which examined the strengths and weaknesses of hundreds of tools aiming to identify those at risk of CSE. Consultations through further focus groups then took place with young people who had survived CSE, and these examined how they would design a new mode of communication and engagement if given a blank piece of paper.

Workshop consultations were then held with young people having equal status to the adults to develop the concept of the project with a project-based artist capturing their ideas onto paper. Young people were encouraged to lead the development of the project and to develop core questions, and they engaged with practitioners, web designers, arts and media specialists and computer engineers. Measures were in place to ensure that young people could lead the consultations with multi-disciplinary practitioners to introduce the novel ideas that they had for the best way to talk to children, young people and young adults. This typified participatory action research **(102, 107, 134, 135)**.

A series of core questions, a website, films and an augmented reality application were then produced. *The Not Just a Thought…* communication model explained a new way of engaging with children and young people to

identify more effectively those at risk of harm and those who have suffered from harm, as well as those children and young people with worries about their lives. This included core and supplementary questions as well as a model of engagement, co-designed with children and young people **(3)**.

The participatory action research **(105)** used in this study involved a systematic approach enabling the participants to find effective solutions to problems they confront in their everyday lives. The focus of the work was to enhance professional and community practices, with measures to ensure the wellbeing of the children and young people involved in the work was always protected.

For at least two decades qualitative approaches to research such as case history, grounded theory and ethnography have been acceptance as equal in value to quantitative approaches such as laboratory experiments, mathematical modelling and statistical analysis **(103)**. Participatory action research can be considered to be a unique method of qualitative research, which involves both theory and practice. It is an iterative process that involves practitioners and researchers working together on a particular cycle of activities including problem diagnosis, reflective learning and action intervention **(103)**.

There are a number of limitations of participatory action research. The research design, the categories of people participating and observed, and the situations in which the research takes place may all be restricted by the purpose of the action programme. The context of the contact between participants and researchers may limit the relationship and personality dimensions being observed. In addition, the role of the researcher as perceived by the

participant(s) in the research may limit the data adduced **(106)**. Notwithstanding the potential limitations, the aims and methods of the participatory action research programme may reveal new dimensions of culture and personality, a participatory action research programme offers the opportunity to study people while they work with the researcher(s) and there is the opportunity to observe people in an intense relationship and at a deep level **(106)**.

The method for this study was chosen so as to work collaboratively with children and young people over a period of over a year, to empower them to be equal partners in the leadership of the development of a new communication tool, and to positively reward them for their work as the project developed through a process of continuous assessment of the materials produced.

Core Paper (4)

This qualitative participatory action research study involved a whole-day consultation workshop (focus group) with 56 children from two Greater Manchester Schools. The workshop, supported by facilitators, involved different methods of data collection during the day:

- "I once knew a young person who..." explaining anonymised stories of children and young people with mental health difficulties, bereavement, bullying and abuse to put into context the day;
- 2. "Steve: a day in my life" drama;
- 3. Bharatanatyam dance;

- 4. Messages to the Mayor;
- 5. Small groups considering who helped the young people, where they went for help and who they approached for help in a number of scenarios;
- 6. Values of the Advocacy House;
- Graffiti floor, wishes and worries tree, and video diary room (a variant of the draw, write and tell methodology (136));
- Developing artwork (based on the draw and write methodology (137, 138));
- 9. Questions to the Mayor and a local Member of Parliament; and
- 10. A plenary session.

This workshop adopted a mosaic approach **(139)** involving a range of childfriendly data collection strategies that respond to the developmental ability and communication preferences of children with different abilities. The approach was chosen to give children maximum ability to participate in the workshop with independent choice of a range of activities available to suit their preferred method of engagement. Regulated health and social care professionals and teachers were available throughout the day to deal with any potential safeguarding issues that were raised and the school's teachers, all of whom had undergone safeguarding training, were also able to pick up any issues raised back at the school.

Audio and video-recorded data was converted to text manually (with additional field notes for video data). These were themed along with the items communicated on the wishes and worries tree, the views expressed on the graffiti floor, the art work and comments from the Twitter[©] Storify[™] as well as any other insights received from the young people during the consultation day **(4)**.

Focus groups are not simply a discussion between people, but are focused interviews exploring interactions between participants (140). They have become a regularly used research method within the health and social care arena (141). To engage, monitor, encourage, and time-manage a project such as the advocacy house consultation (4) requires excellent group working skills and a great deal of practice. The role of the facilitator is key to ensuring that the interview covers the required ground and allows the opportunity to re-visit specific points (140). Focus groups can be a time-consuming method in relation to analysis; however, the opportunity for interaction with participants, enabling them to explore their perceptions, is an enjoyable and rewarding experience (140).

The action research **(105)** in this study was chosen to enable children to engage with researchers and clinical practitioners to find effective solutions to the issues confronted by children in Greater Manchester in their everyday lives.

Core Paper (5)

This quantitative prospective descriptive study involved a three-round Delphi study **(142-145)** of paediatric emergency medicine, general paediatric and

emergency medicine consultants in the UK and Ireland **(5)** to define significant illness and injury diagnoses in children's emergency medicine. The Delphi questions were distributed, and the responses collated, using the web-based *Smart Survey* **(146)**. Each Delphi round ran for four weeks, separated by four to six weeks to allow analysis and interpretation of responses.

Delphi surveys involve a series of sequential rounds interspersed by controlled feedback to gain the most reliable consensus from a group of experts (143-145). This study adopted a modified Delphi process (145) whereby after each round the statements that achieved consensus were eliminated, and statements that did not achieve consensus were carried through to the next round of questioning. This approach was taken to maximise participation in the study through minimising responder fatigue and is an established mode of conducting consensus-based Delphi research.

Previous work **(78)** was called on to act as a template to classify diagnoses into illness categories then the study group created the list of diagnoses thought to be significant and covering the majority of emergency department attendances. Round one consisted of 161 statements on clinical conditions from the following 17 illness and injury categories.

- Infection
- Respiratory
- Cardiac
- Gastroenterology
- Neurology
- Trauma

- Surgery
- Allergy
- Dermatology
- Toxicology
- Mental Health
- Endocrine and metabolic

- Musculoskeletal
- Haematology
- Renal
- Safeguarding
- Miscellaneous

For each condition, respondents were asked whether they agreed that the condition was significant enough to warrant acute admission to hospital, with admission being used as a proxy for significant illness or injury. A five-point Likert scale was used for answers:

- 1 point: strongly disagree;
- 2 points: disagree;
- 3 points: neutral;
- 4 points: agree; and
- 5 points: strongly agree.

The aim was to use up to three survey rounds in accordance with accepted Delphi practice **(142-145)**. The reliability of Delphi can be defined in terms of the precision of measurement instruments **(147)**. That is, it refers to the dependability of measurement across different replications and procedures for ensuring reliability are critically important **(148)**. There are four main approaches to estimating reliability **(149)**:

- test-retest which involves administering a test on two different occasions to the same sample;
- internal consistency, which assesses the consistency of results across items within a test;
- inter-observer which requires the rating of the same information and the recording of consistent results by different testers; and

 parallel form, also referred to as alternate (150) which is undertaken when two different instruments are designed to test the same information and produce the same results (151, 152).

Validity is divided into external validity, which measures the generalisability of the findings, and internal validity which refers to the confidence placed in the cause and effect relationship, normally demonstrated by experimental research (149, 153, 154). The Delphi methodology chosen in this study suited the research question posed although It is accepted that utilising focus groups (155-157), perhaps via the PERUKI network, would have been an alternative approach.

The methodology used estimated reliability of the findings by using "test-retest" which involved multiple Delphi rounds on different occasions with the same sample of respondents. The study team set group consensus as a priori 80% agreement either side of the Likert scale, that is 80% total of strongly disagree and disagree (negative consensus), or 80% total of strongly agree and agree (positive consensus). Accepted practices of Delphi consensus parameters often quote a threshold of 70% agreement, though this is not a rule **(143, 144, 158)**. Since a proxy outcome for significant illness (admission) was being used, a higher threshold was chosen to ensure that the level of consensus was more robust.

In round one, respondents had the opportunity to suggest additional conditions and scenarios they thought would warrant hospital admission from the ED. These suggestions were then tested in round two. Round three only included

statements suggested by round one respondents which did not achieve consensus in round two.

Statements that had been carried through from round one to round two were not included again in round three as they had already been through the process of expert opinion retesting. All statements not achieving consensus after a single round of testing were, therefore, given an opportunity for the second round of retesting.

For statements on which consensus was reached **(APPENDIX TWO)**, median and inter-quartile ranges were calculated from the five-point Likert scale results. For statements which did not reach consensus, medians and inter-quartile ranges were used to demonstrate the spread of opinion in the responses. Analysis was conducted using *MedCalc* Statistical Software **(159)**.

Core Paper (6)

This quantitative prospective observational study of the diagnostic accuracy of PAT-POPS and ManChEWS for admissions of children from the emergency department involved children aged under 16 years attending the ED of a hospital in Greater Manchester. The reference standard for the study was admission to hospital within 72 hours of first attendance to the ED. This was a prospective study of a consecutive series of patients: data collection was planned before the index tests and reference standard were performed. The decision on whether to admit a child to inpatient care was made by the clinician seeing the patient, using their subjective clinical experience as well as departmental guidelines, including ManChEWS. The disposal outcome

(discharged or admitted) for each attendance was recorded on the electronic patient record. Information was collected on re-presentations. A child admitted following re-attendance at the ED with the same clinical problem within 72 hours was counted that as an admission for the original presentation. Data on admission were recorded by hospital staff in the hospital electronic record, and then extracted by the research team retrospectively.

ManChEWS is scored Green, Amber or Red **(64)**. All observations must be within the normal range for the age of the child for the award of Green status. Any physiological parameters that are abnormal, but within the defined range, lead to Amber status. Any parameters that are very abnormal and which lie outside of the Green or Amber ranges result in a Red status, indicating that the child has potentially significant physiological disturbance.

PAT-POPS version 1 (6, 7, 160) is assessed as a score between 0 (likely low risk of serious illness) and 18 (likely high risk of serious illness) and is a checklist which quickly scores acutely ill children on age-related physiological measures (heart rate, respiratory rate, temperature) and behavioural and risk-identifiers (such as oxygen saturations, breathing pattern, conscious level, nurse's judgement of how well the child is, child's behaviour) using easy to collect data. Measurements of the physiological variables and subjective assessments necessary to calculate ManChEWS and PAT-POPS for each patient were taken by nursing staff in the ED either at the point of triage or during the child's assessment in the ED. Training of the nursing staff to ensure observations were performed routinely and there was familiarity with both ManChEWS and PAT-POPS both contributed to inter-rater reliability.

Observations were performed, in accordance with the routine clinical assessment established in the emergency department, as early as possible in the patient's journey, prior to an admission-decision being made, to reduce the likelihood of bias.

The age, gender and diagnosis of the sample of 2068 patients were reported using descriptive statistics. The size of the sample was adequate for the various statistical tests employed during the analysis phase of the study. The sensitivity and specificity of PAT-POPS and ManChEWS to predict admission was calculated and presented as comparative ROC curves. The positive and negative likelihood ratios at different cut points of PAT-POPS and ManChEWS were reported (161). 95% confidence intervals and p-values, as appropriate, were presented. The sensitivity and specificity of PAT-POPS to predict admission for separate groups of children with illness or trauma was compared using ROC analysis (162). The data were entered into Microsoft Excel and analysed using STATA version 13 (163).

The *c* statistic, or area under the ROC curve, is popular in diagnostic testing in which the test characteristics of sensitivity and specificity are relevant to discriminating between two outcomes **(164)** (in the case of the PAT-POPS and ManChEWS study: admission to, or discharge from, hospital). The performance of a diagnostic test in the case of a binary predictor can be evaluated using the measures of sensitivity and specificity. For predictors that are measured on a continuous or ordinal scale, it is desirable to assess performance of a diagnostic test over the range of possible cut-points for the predictor variable. This can be achieved by drawing a ROC curve that includes all the possible decision

thresholds from a diagnostic test result **(165)**, and that method was ideally suited to ascertaining the diagnostic power of PAT-POPS versus ManChEWS regarding their ability to predict risk of admission of children from an ED.

Core Paper (7)

The full protocol of the intended method of this quantitative prospective observational cohort study with internal and external validation of a clinical prediction tool is available **(7)**. At the time of writing this thesis, data had been collected and analysed, and the results had been written-up into a paper submitted for open-access publication though not yet accepted. Core paper 7 describes the background and methodology that was planned to refine and test the accuracy of PAT-POPS to predict admission and discharge of children who attend an ED. It would be bizarre to pretend that it was not known at the time of preparing this chapter that the study had been conducted as planned. This commentary on the core paper continues, therefore, to report what was done.

The substantive study was an observational cohort study with internal and external validation of a clinical prediction tool. The study was carried out in two general emergency departments and an urgent care centre in Greater Manchester, UK. Children 0-16 years of age who attended any one of the sites were recruited prospectively over one year using opt-out consent **(166-170)**. This was a significant decision. The study could have been done without consent, but we were determined to follow the guidance of our parent advisory group and seek consent in a condensed format. Our previous work with children had also taught us that they would be willing to participate but would want to be informed and asked if circumstances allowed.

The outcome measure was admission to hospital, either on first presentation or with the same complaint within seven days. This definition was made after listening to the parent advisory group which saw this detail in more simple terms than did the research team.

The study was supported by a patient advisory group which provided input to the programme of research. This patient advisory group met with one author during the study. Patients partnered with the study team for the design of the study and the informational material to support the opt-out consent process.

At the time of publishing the protocol for this study, PAT-POPS version 1 was available and this included age, heart rate, temperature, respiratory rate, oxygen saturation (%), requirement for supplemental oxygen, breathing, responsiveness (using the AVPU method: conscious level <u>A</u>lert or responds to <u>V</u>oice or responds to <u>P</u>ain only or patient is <u>U</u>nresponsive), nurse judgement, behaviour and presence of chronic condition(s) as variables. In the study, in addition to the PAT-POPS version 1 variables, the following additional variables were included: arrival by ambulance; day of the week; time of the day; referral by health professional; attendance with same problem in previous week. In doing this we sought to enhance the validity of the study by ensuring that potentially important variables were considered for inclusion in the final tool.

A clinical prediction model was developed using children from one hospital site, with hospital admission as the outcome and including clinical and observed measures. Internal validation was performed by applying the original model to 500 bootstrapped samples, followed by external validation on data from two

other hospitals. The model's regression coefficients were used to develop a point scoring system for use by ED clinicians.

The variables proposed in the published protocol (7) were those considered for inclusion in the PAT-POPS version 2 tool. In the protocol it was estimated that 9000 children were needed for the development of the prediction model and 7000 children in the independent validation (16000 children overall). More data than needed was allowed for (and this approach was granted at ethics review) due to the need to collect data for a full year to capture seasonal variation in childhood illness and injury. Intermittent data collection would not help implementation of the tool and would have required the employment of specific staff for the project, which would have been significantly more costly. Ultimately, 44501 children were recruited into this study and at the time of writing this thesis the study was the highest recruiting children's research study ever in the history of the UK National Institute for Health Research (NIHR) Clinical Research Network (CRN).

Data analysis was conducted in STATA version 14 (163) using two-sided 95% confidence intervals and the 5% significance level. Analysis was reported according to the TRIPOD (171) and STARD (172) reporting guidelines. Final analysis was undertaken after all data had been entered into the database, and the database had been cleaned and locked. Children were excluded from the analysis if the outcome variable (admission) was missing or if all the independent variables were missing. For variables with over 4% rates of missingness data was imputed using hot-deck imputation (173). This involves stratifying patients by key predictive variables (injury/illness status, admission)

status and age) and replacing missing values with those of a patient from the same strata.

Patients were described with respect to the variables in the model, both overall and by site, reported as number (%) for categorical variables; mean (standard deviation, minimum, maximum) for normally distributed variables; median (interquartile range, minimum, maximum) for other numeric variables.

Children from one hospital site were utilised for the model development. Logistic regression models were developed with hospital admission as the outcome and including all candidate variables. Due to several of the variables being non-linearly associated with the outcome a closed test procedure was used to determine the best functional form of each continuous variable and concurrently whether it should be included. This involved starting with a model that included all potential predictors and testing the best fitting fractional polynomial form of each continuous variable individually **(174)**.

Variables were removed from the model according to p-values with any less than 0.10 being excluded. For categorical variables, if at least one category was significant all were included initially. Quality of the data and risk of bias was assessed using PROBAST **(175)**.

The calibration score and calibration slope were examined to assess how well the predictions from the model matched the data and calibration plots were used to compare agreement between predicted and observed injury and illness. Discrimination was also considered, to measure how well the model separated

between individuals who were admitted and those who were not (C-statistic, which is equivalent to area under the ROC curve).

Internal validation was performed by applying the original model to 500 bootstrapped samples. The discrimination and calibration performance of the model in each of the bootstrap samples was compared with the model fitted to the original data to provide a measure of optimism. The inclusion/exclusion of any predictors which featured in the selected model but only rarely across the bootstrap samples (or vice versa) was noted. The output of stage 1 and 2 was the new PAT-POPS version 2 tool. External validation using data from two other hospitals. The developed model was applied to each external dataset, and calibration and discrimination measures were reported.

The model's regression coefficients were used to assign integer points to each level of each risk factor, and a reference table of risk per possible points total was produced. Together these provide a clinically useful score. By applying the points scores to the development dataset, it was possible to calculate the sensitivity, specificity, positive and negative likelihood ratios of the PAT-POPS version 2 tool (index test) in predicting admission (reference test) with 95% confidence intervals.

At the end of the study, the patient advisory group commented on the suggested cut-offs for the developed PAT-POPS version 2 score. A consensus meeting was held with participation from the research team, plus paediatric ED clinicians and an independent methodologist. The usefulness of the PAT-POPS version 2 tool was assessed by calculating the sensitivity, specificity, positive

and negative likelihood ratios at the chosen cut-points, to predict admission and discharge.

An overall ROC curve is most useful in the early stages of evaluation of a new diagnostic test. Once the diagnostic ability of a test is established, only a portion of the ROC curve is usually of interest, for example, only regions with high specificity and not the average specificity over all sensitivity values **(165)**. For this reason, units interested in using the new PAT-POPS version 2 tool will need to look carefully at the portion of the ROC curve for the version 2 tool with the most appropriate sensitivity and specificity for their local circumstances.

SUPPLEMENTARY PUBLICATIONS

In this thesis the detailed methodology reported in the supplementary publications is not described as these supplementary publications merely support and underpin this thesis – they are not the core publications upon which this thesis primarily relies. Nonetheless it is worthwhile summarising the methods used in these supplementary publications, with explanations being provided where these methods differ from those in the core publications.

Supplementary published work 8 was a descriptive qualitative impact analysis study explaining the impact, summarised in chapter six of this thesis, resulting from studies carried out between 2014 and 2019. This method was chosen as it was the most appropriate way of describing the impact and conclusions of a wide variety of studies over a five-year period.

Supplementary published work 9 used mixed methods, with ethnography as the dominant means of data collection and analysis, and a pragmatic paradigm to describe the lives of families living around Sihanoukville, Cambodia. This included a description of the health issues affecting children and their families and the plans put in place to manage these. The pragmatic paradigm refers to a worldview that focuses on what works rather than what might be considered absolutely and objectively true or real **(108)**.

In addition, a new programme of first aid training was evaluated using survey responses and interviews, and through consultation with children and young people in focus groups the accelerated education provided at M'Lop Tapang (176) was also evaluated (9, 177). A new education and learning resource area was also created and a model of practice for rapid education updates was instigated.

Supplementary published work 10 was a precursor to published work 2 and used the same methodology as the substantive paper on mandatory reporting of FGM, chosen for the same reasons.

Supplementary published work 11, funded by the Winston Churchill Memorial Trust, used pragmatic mixed methods with ethnography as the dominant method of data collection and analysis to investigate policies, practices and procedures in the USA, Malaysia, Singapore and Cambodia which, with modification in the UK, might turn the tide of child abuse and neglect and better safeguard children and young people from harm. In essence, the study

investigated overseas initiatives, asking the question, "does this initiative have the potential to make a difference in the UK?".

Supplementary published work 12 was a quantitative prospective descriptive study using audit techniques aimed to assess the effectiveness and safety of rectal paraldehyde in the management of acute, including prolonged, tonic– clonic convulsions. At the time of publication there were very limited published data on the effectiveness and safety of paraldehyde, and data published prior to this paper mainly focused on its intramuscular route of administration. There was a significant gap in the evidence base for clinical practice.

Data from four participating hospitals were collected on each dose of paraldehyde used for the treatment of tonic–clonic convulsions over a period of one year. Data were not collected on its use in non-convulsive or unclassified status epilepticus. Information was recorded on a proforma which was piloted and distributed to all clinical areas where rectal paraldehyde was in common use throughout the hospitals, including the emergency departments and the paediatric medical wards, and the neurosciences unit, high dependency unit and paediatric intensive care unit.

The following data were collected: date of birth, date of administration, child's weight, dose of paraldehyde administered, whether paraldehyde was the first drug to be administered for the convulsion being treated, if prior medication had been used for this convulsion, whether or not paraldehyde stopped the convulsion and how long this took, if the patient required any additional anticonvulsant within one hour following cessation of the seizure terminated by

the use of the paraldehyde and whether or not the patient experienced any respiratory depression following administration of the paraldehyde. Proformas were completed after the administration of each dose of paraldehyde by the senior, trained ward nursing staff.

All children in the study met the criteria for a prolonged tonic–clonic seizure (empirically defined as a tonic–clonic seizure lasting longer than five minutes) (84). Seizure (convulsion) termination was defined as the seizure having stopped for a minimum of 10 minutes. Respiratory depression was defined as a fall in oxygen saturation or decrease in respiratory effort sufficient to require assisted breathing either via face mask ventilation or intubation, within 15 minutes after administration of the drug (178). Where an individual child received paraldehyde on more than one occasion, data for each episode were entered and subsequently analysed separately. Any missing data were collected retrospectively from the patient notes at the end of the audit. This method of undertaking the research helped to ensure neutralisation of any confounding variables thus maintaining the reliability of the findings.

Discussion with the research and development department at Alder Hey Children's Hospital confirmed that this was an audit of a treatment and consequently ethical approval was not required. All data entry was anonymised. Although the Health Research Authority does not consider audit to be research (179), clinical audit, if appropriately carried out, is a valuable tool to improve the quality of care of patients (180, 181).

SUMMARY

The published works underpinning, and supporting, this thesis involve three primary research methods **(88-97)**: qualitative, quantitative and mixed methods research, including the use of Delphi **(142-145, 158)** methodology. In addition, selected publications use clinical audit **(180, 181)**, pragmatic paradigm **(108, 182)** and ethnography **(99-101)**.

In this thesis a critical appraisal of the core publications is used as a descriptive tool to outline the limitations and my subsequent critical reflections of each publication together with their individual and collective contribution to knowledge. The unifying model is described together with key messages for research and society, and impact resulting from the portfolio of published works referenced herein.

4: CRITICAL APPRAISAL OF CORE PUBLICATIONS

INTRODUCTION

I work as a consultant in children's emergency medicine. I trained via a paediatric route, completing general paediatric training with subspecialty accreditation in paediatric emergency medicine, sufficient to enter my name on the Specialist Register of the UK General Medical Council in both General Paediatrics and Paediatric Emergency Medicine. I was awarded Fellowship of the RCPCH (FRCPCH) upon taking up my substantive post as a consultant. In addition, I was awarded Fellowship by Election by the then College of Emergency Medicine, FRCEM) in recognition of my work in children's emergency medicine. The award of FRCEM by election is no longer available as a route to fellowship. Candidates for the award must now sit an examination which includes a critical appraisal component.

I have therefore decided to structure this section of the thesis as a critical review of each of my core published papers using a structure **(183)** that would be broadly recognisable to a candidate appraising a paper in the higher (Fellowship) component of the Royal College examination. The structure in this chapter is to review the paper-specific background information showing how the individual paper sits within the context of other work, to describe the methods, results and conclusions of the study and, perhaps most importantly, to describe the study's limitations by a process of critical reflection.

PAPER (1): PHYSICAL PUNISHMENT OF CHILDREN

Background

At the time of publication of the paper on *Physical Punishment of Children: time to end the defence of reasonable chastisement in the UK, USA and Australia*, 52 states had reformed their laws to clearly prohibit all corporal punishment of children **(1)**. By March 2020, this number had increased to 59 states that have full prohibition of corporal punishment of children and 29 states that had committed to reforming their laws to achieve a complete legal ban **(184)**.

In 1979 Sweden was the first country to prohibit physical punishment of children. Within the UK, Scotland (2019) **(48)** and Wales (2020) **(111)** introduced legislation to provide equal protection to children and, in effect, prohibit their physical punishment **(184)**.

The Global Initiative to End all Corporal Punishment of Children produced emergency guidance on 19 March 2020 recognising that at times of national stress, when schools may be closing and anxiety levels in the population may be increasing due to the SARS-CoV-2 COVID-19 pandemic⁴, children may be at higher risk of physical punishment in their homes **(185)**.

The study focused on the legislative change that is necessary to protect children better, to assist health professionals in recognising children at risk of

⁴ <u>https://www.who.int/emergencies/diseases/novel-coronavirus-2019/technical-guidance/naming-the-coronavirus-disease-(covid-2019)-and-the-virus-that-causes-it</u>

harm, and to encourage attitudinal change in the wider community with the hope of progress towards a better and more supportive environment in which children can grow up safe from physical punishment **(1)**.

Method

The research study employed a mixed-method design and had two main components. A literature review was conducted to establish the effects of physical punishment of children and the steps that countries around the world have taken to protect children from corporal punishment. Consequently, a legislative review was completed of international law and the specific position in the UK, USA and Australia regarding whether and to what extent physical punishment of children is either permitted or prohibited. Analysis of this data by a multi-disciplinary team involving a social worker, lawyer and doctor, enabled key recommendations to be made for legislative change in the UK, Australia and the USA.

Limitations And Critical Reflection

The law is best seen as enforcing what a society is prepared to accept as appropriate conduct, and caution must be exercised when introducing aspirational legislation which may not have the immediate support of a significant fraction of society. This study was a review of literature already published around the world and a legislative review in three specific countries, also in the context of international law.

Although Scotland and Wales have introduced legislation to give children the same rights to protection from assault as adults following consultation with the

public, such discussions with the public in England and Northern Ireland have yet to begin before the administrations can consider the introduction of legislation.

There are some complexities in a comparative exercise between the USA, which has not ratified the UNCRC, and Australia and the UK (which has enacted the Human Rights Act 1998, effectively importing principles contained within the Human Rights Convention) **(30)**. There is some divergence in jurisprudence between the three countries.

The paper was, effectively, desktop research without consultation with members of the public, and the paper was a key piece of evidence which underpinned the decisions of the Scottish Parliament and Welsh Assembly to introduce childprotective legislation. In order to provide further evidence for future legislative considerations in England and Northern Ireland, it would be beneficial to undertake consultation with both children and adults to ascertain if the research findings would receive public support in those jurisdictions. If it would not, it would be helpful to know what further evidence would be convincing.

Results

Physical punishment of children is the use of physical force with the intention of causing the child to experience bodily pain or discomfort sufficient to correct or punish the child's behaviour **(186-188)**. Physical punishment differs from physical restraint – that which may be necessary to protect a child from self-harm or from harming others.

Some proponents of physical punishment of children believe that this is thought to teach respect for authority and that failure to punish children physically leads to uncontrolled, disrespectful, acting-out behaviour. This implies that the lack of sufficient discipline increases the level of societal discord and violence (189). Not everyone agrees that corporal punishment of children is inherently wrong, with views being expressed that occasional smacking does no harm (190) and that although the harmful effects of physical abuse and other extreme punishments are clear, a blanket injunction against spanking is not justified (191). In Singapore, for example, physical punishment of children by caning was stated to be a widely accepted form of physical punishment and was regarded by the fewest respondents in public research to be 'never acceptable' or 'abuse/neglect' (192).

In contrast, Article 19 of the UNCRC (31) requires that "... States Parties shall take all appropriate legislative, administrative, social and educational measures to protect children from all forms of physical or mental violence, injury or abuse, neglect or negligent treatment, maltreatment or exploitation, including sexual abuse, while in the care of parent(s), legal guardian(s) or any other person who has the care of the child." Physical punishment of children is therefore clearly counter to the UNCRC which confers absolute protection for children against violence while in the care of any person.

Although not all studies have shown that corporal punishment of children is always associated with poor outcomes **(193, 194)**, the overwhelming evidence is that physical punishment of children is harmful to them on a population basis. Children who are physically punished are at risk of significant harm, with those

that have been smacked by their parents being seven times more likely to be seriously assaulted (for example punched or kicked) than those who have not been physically punished, and more than twice as likely to suffer an injury requiring medical attention than those who have not been smacked **(195)**.

Between two and seven percent of mental disorders have been attributed to physical punishment of children **(196)**. Whilst it is axiomatic that laws function better to eradicate behaviour when combined with education and supportive measures, it is difficult to see how tackling family violence will be achieved when punishment of children by physical violence remains a defence under criminal law, particularly when the concept of reasonableness is such an ambiguous and subjective term **(1)**.

Physical punishment of children is rife. It remains an embedded societal norm, but it is no more effective as a long-term strategy for improving behaviour than other approaches **(197)**, and reliance on physical punishment makes other disciplinary strategies less effective **(198)**.

Conclusions

This study's examination of international law exposed that the purpose of internationally accepted principles is to protect children from violence. This is undermined by domestic legislation which condones family violence in the name of punishment of children and creates insuperable difficulties for clinicians trying to distinguish cases of a child at risk from abusive parents from those in which a parent who is otherwise caring had a momentary loss of control. The

consequence is that the continuation of a defence of lawful chastisement of children allows for the abuse of children to remain hidden (1).

To discipline children through physical violence merely serves to educate them that such violence is accepted and encouraged by society, which may teach them to behave in that way as they grow older. Moves to prevent family violence are progressive, but the position of a society where physical punishment of children is permitted yet child abuse is forbidden is not a tenable one.

A liberal society must not ignore wrongs committed by adults against children. However, a society must be careful about passing too many laws that are aspirational in nature and which that same society is not prepared to enforce. Accordingly, if there is to be legislative change, that change must rigorously enforced. It must not result in a law that is weak and ignored both by those people to whom it is intended to apply and those whose function it is to investigate alleged breaches. Any such legislative change must find a way of diminishing human suffering, increasing human equality, and increasing the ability of all children to start and continue their lives with equal chances of happiness **(39)**.

Trying to achieve social change by passing laws can be difficult. If a situation in society is viewed as being so serious that a law is required to achieve a change whether it be secondary prevention measures such as the reporting of alleged offences or the primary prevention of those same offences, that legislative

change must be accompanied by a whole raft of associated material including, for example, a full evaluation of the effectiveness of the new legislation.

The law may not change society in the short-term, but it is the measures that are put in place associated with that law that are important. Reducing the number of cases of child abuse must begin with a clear message from society that physical punishment of children whatever the circumstances is unacceptable. Preferably, society should come to that conclusion by itself and demand a change in the law. If this demand is not forthcoming in a timely fashion, the law-makers in that society, must take the brave decision. Despite some opposing public opinion, since the situation is sufficiently serious, they must introduce aspirational legislation to provide equal protection to children and to prohibit physical punishment. This is the case in England and Northern Ireland, and, indeed, in other countries around the world where physical punishment of children remains legal **(1)**.

There is a direct link between this study's conclusions and the theme of my thesis. This study considered the legislative change that is required to protect children and young people better from physical punishment – in effect an assault. The study also explained why advocating for children and young people is necessary – directly linking with the advocacy theme in this thesis – as it is clear that there are those who do not believe that prohibition of physical punishment, and introduction of equal protection, is necessary at this time. In addition to proposing legislative change there is a clear need to advocate for children and young people at a national and international level to gather together support for such legislative change, and to try to change the hearts and

minds of those who oppose it (or will oppose it). That advocacy is best underpinned by research evidence which therefore links directly to the third theme running through this thesis – that of pragmatic child health research to improve the health and wellbeing of children and young people; especially that where the results can be implemented within a short timeframe.

PAPER (2): MANDATORY REPORTING OF FEMALE GENITAL MUTILATION

Background

While FGM has been illegal in the UK since 1985, and taking children abroad for the procedure has been a criminal offence since 2003 **(40)**, British-born girls are still being subjected to this abhorrent form of abuse with 112 cases being reported in 2016-2017 **(199)**. Research by City University in 2015 estimated that there were more than 100,000 women between the ages of 15-49 years of age living in the UK who have had FGM **(42)**. Since October 2015 **(41)** health and social care professionals and teachers in England and Wales have had a mandatory duty to report FGM cases to the police in which either a girl (under 18 years of age) informs the professional that FGM has been carried out or-a professional observes signs consistent with FGM.

The study examining *Mandatory reporting of FGM in children in the UK* focused on data collection about FGM since the introduction of mandatory reporting in 2015. The paper was aimed at health professionals, in particular midwives, to

increase their understanding of the legal implications of FGM and how UK police authorities have responded to changes in the law (2).

Method

Email requests were sent to all 45 UK police authorities under the provisions set out in the Freedom of Information Act 2000 **(114)** as follows:

- Please supply data on how many cases of Female Genital Mutilation (FGM) were reported to your police force each month between 31
 October 2015 and 21 February 2016, stratified, if possible, by age of alleged victim and occupation of person making the report.
- Please supply data on how many cases of FGM were reported to your police force each month between 31 October 2014 and 31 October 2015, stratified, if possible, by age of alleged victim and occupation of person making the report.
- 3. Please supply data on the age-breakdown, sex-breakdown and total population of your police force area in 2014 and 2015. If this is not possible, or you do not hold this data, please let me know as I would not wish this to detract from the above two requests.

Similar requests were also sent to NHS England, the Home Office, the Health and Social Care Information Centre (now NHS Digital) and the Department of Health, asking how many cases of FGM had been reported to the organisation within the given timescales. The Office for National Statistics was asked to supply data on the age-breakdown, sex-breakdown and total population of each local authority area.

Limitations And Critical Reflections

The Freedom of Information Act 2000 includes provision for an appeal to be lodged if the applicant is dissatisfied with the response from the public authority and believes that this is not in accordance with the legislation. In this study all internal appeal procedures were followed, where necessary, if a negative response was received to the first request. However, there was no escalation to the Office of the Information Commissioner when internal appeal requests were rejected. While such an appeal to the Office of the Information Commissioner may have been legally possible, the focus of enquiries was on the ease, or otherwise, with which such important data could be accessed and analysed. Appeals took on board that the way in which data were collected may contain private data that would require ethical approval to access.

This study showed that information on FGM was difficult, if not impossible, to obtain by an academic attempting to evaluate the introduction of mandatory reporting of FGM, or by a member of the public with an interest in this subject area, perhaps wishing to express a view on the 2016 consultation on generic mandatory reporting of child abuse.

Results

The Health and Social Care Information Centre reported that from October 2014 to October 2015 there were on average 481 new reports of FGM each month across England. By comparison, 145 cases of FGM were reported by three police forces (combined) for the same period, with three police authorities reporting that no cases of FGM were reported to them, and the remaining police authorities either declining to provide information, citing an exemption under the

Freedom of Information Act 2000, or provided information only in aggregate form which was difficult or impossible to analyse. The Home Office reported that FGM was recorded alongside crimes such as 'assault occasioning actual bodily harm' as an aggregate under category 8N and so specific data for FGM was unavailable.

Conclusions

The ability of frontline professionals and policymakers to interpret FGM incidence and prevalence data and to respond to the needs of affected women and children is affected by the secrecy that surrounds the performance of FGM, the complexities of investigation and the absence of significant numbers of prosecutions.

It was recognised that requesting data where there was a small number of cases may have caused concern that data would be used for a private investigation into what had been reported by whom, and to put pressure on people not to cooperate with the authorities. However, given that there is strictly limited access to data on FGM investigations, this is an unreasonable barrier to measuring the success of community eradication initiatives. Whether FGM is being tackled and whether responses are effective simply cannot be seen. Although the Home Office has now changed data collection provisions to collect FGM data separately from other assaults, there continues to be inadequate public disclosure of FGM data to enable full evaluation of the mandatory reporting law. A follow-up paper on the law surrounding FGM Protection Orders was submitted to a journal in March 2020 and is currently under review.

This study found that police authorities were not collecting data or responding to requests for information in a consistent fashion. The lack of effectiveness of FGM mandatory reporting could provide a useful background to decisions regarding mandatory reporting for all forms of child abuse. It was recommended that aggregate national data should be collected by a central authority, led by an FGM Commissioner, and that NHS data should be collected against the same criteria as police data, with clinicians' recordings being made subject to similar aggregate analysis.

Further, it was recommended that new guidance be provided to police authorities to respond to requests for information where anonymous statistics rather than case-specific facts are being sought. Point 55 from the Government's Violence against Women and Girls Strategy 2016-2020 (200) requires the development of a meaningful action plan for FGM data. The issues identified in our study suggest that mandatory reporting and recording of FGM is more symbolic than effective.

This study demonstrates the inextricable link between health, law and advocacy. FGM is an abhorrent crime with hugely deleterious effects on the health and wellbeing (both mental and physical) of the girls and women who have been subjected to it. It is absolutely right that there has already been legislative change to prohibit FGM and to introduce mandatory reporting of it. However, this study has highlighted the need for full academic evaluation of that law. Advocacy is crucial for those people who have already been subjected to FGM and those who could be protected from FGM in the future as it is not just further legislative change that is needed. It is a raft of public policy measures,

including the appointment of an FGM Commissioner at a national level, that will drive forwards further improvements with consequent benefits for girls and women throughout the UK.

REPORT (3): NOT JUST A THOUGHT...

Background

Healthcare decision-making involving children and young people can be a difficult process, especially in situations of serious illness. When children are ill, adults have an understandable desire to protect them from difficult decisions and to shield them from unpleasant information. Yet, children and young people want and need to be heard by healthcare professionals and to be provided with age-appropriate explanations and information in order to help them cope with the consultation and treatment processes. There is a need for better training for professionals in dealing with both children and parents, and more research is needed into how participation works in practice and into the impact of factors such as social exclusion or other forms of disadvantage on participation.

Participation covers a broad continuum of involvement in decisions; it is a multilayer concept involving many different processes. For example it can simply mean taking part, being present or consulted or, alternatively, it can denote a transfer of power so that participants' views influence decisions with hierarchical or non-hierarchical distinctions between levels of participation according to the degree of power that is shared or transferred or the circumstances of the participating children.

Child abuse is an appalling crime against some of the most vulnerable in society. In March 2020 the Office for National Statistics (ONS) compiled a range of indicators from different data sources to enable better understanding of the extent and circumstances of child abuse. Its statistics on abuse experienced in childhood in England and Wales include data on sexual abuse, physical abuse, emotional abuse and neglect. The release also includes statistics on child abuse and the criminal justice system **(201)**.

The ONS reports that there is no source providing the current prevalence of abuse during childhood. The Crime Survey for England and Wales is said to provide the best available indicator of prevalence by measuring the prevalence of adults who experienced abuse before the age of 16 years. This is an underestimate of child abuse as abuse against children of 16 and 17 years is not included.

In the year ending March 2019 (the latest available figures), it was estimated that approximately 8.5 million adults aged 18 to 74 years experienced abuse before the age of 16 years. This is equivalent to 20.7% of the population aged 18 to 74 years (201). At 31 March 2019, 52,260 children in England were the subject of a child protection plan and 2,820 children in Wales were on the child protection register because of experience or risk of abuse or neglect. Neglect was the most common category of abuse in England, and emotional abuse was the most common in Wales. At the same date, 49,570 children in England and 4,810 children in Wales were looked after by their local authority because of experience or risk of adults (52%) who experienced abuse before the age of 16 years also experienced domestic

abuse later in life, compared with 13% of those who did not experience abuse before the age of 16 years (201).

Those who work with children and young people have government guidance on how best to work together to safeguard children **(202)**. The qualities children look for in someone who they think can help them have been reported **(203)**, including being a good listener, warm, honest, and approachable but professional in the way that they behave so that children can trust that action will be taken.

The challenge is how to demonstrate these qualities to children and young people, especially when a practitioner might see them only once and for as little as ten minutes. Therefore, a key aim of the development of the *Not Just a Thought...* communication model was to ensure that it was co-produced with children and young people to support an equitable design which nurtured confident engagement and leadership.

Method

This study began with a theatre play called "Somebody's sister, Somebody's daughter" and a discussion of the issues that it raised with children, young people, parents and practitioners. Consultation events were then held in Manchester and Dorset with multidisciplinary practitioners which examined the strengths and weaknesses of hundreds of tools aiming to identify those at risk of child sexual exploitation. Consultations then took place with young people who had survived child sexual exploitation, and these examined how they would

design a new mode of communication and engagement if given a blank piece of paper.

Workshop consultations were then held with young people having equal status to the adults to develop the concept of the project with a project-based artist capturing their ideas onto paper. Ideas were readily forthcoming, and the young people created the project name. Young people were encouraged to lead the development of the project and to develop core questions, and they engaged with practitioners, web designers, arts and media specialists and computer engineers. Measures were in place to ensure that young people could lead the consultations with multi-disciplinary practitioners to introduce the novel ideas that they had for the best way to talk to children, young people and young adults.

A series of core questions, a website, films and an augmented reality application were then produced. *The Not Just a Thought...* communication model explained a new way of engaging with children and young people to identify more effectively those at risk of harm and those who have suffered from harm, as well as those children and young people with worries about their lives. This included core and supplementary questions as well as a model of engagement, co-designed with children and young people (3).

Limitations And Critical Reflections

Once the model had been finalised, it was important to test it with young people and professionals before introducing it to general use. The approach taken was to simulate exchanges between young people (secondary school students) role-

playing from a scenario briefing with a mixture of nursing and social work professionals using the model to ascertain the young person's hidden issue. A counsellor was also in non-participant attendance in case of unexpected distress **(204)**.

There was overall approval from the professionals, who recognised that the greatest value of the model lay in providing support to less experienced practitioners, and in its basis in the extensive work undertaken with young people to establish the right questions and an appropriate approach to provide opportunities for a positive dialogue. Reducing the use of less helpful questions which could cause the young person to lose trust and to decline to seize the opportunity to divulge a problem and secure support was also highlighted **(204)**.

During testing it was found that the model allowed young people to feel more at ease with the discussion, offering the opportunity for them to divulge sensitive information or a troubling issue rather than the professional demanding information. Professionals felt empowered to enter into difficult discussions on sensitive topics. They found the model easy to apply with minimal preparation, and despite the outstanding acting by the young people with convincing portrayal of distress and embarrassment still felt the conversation to be safe and enabling. They wished to see it adopted into practice. The professionals were clear that experienced professionals would probably incorporate the model into their existing practice fairly seamlessly, but the greatest impact would be on the practice of less experienced workers. For these, the model would provide structure and confidence.

The physical context of the encounter became less important if the professional approach was right. Using the whole model rather than closing down too early once a serious issue has been divulged and moving to solutions was held strongly to be an important mechanism. Training in the use of the model will be essential, and training that could mimic the simulation approach adopted for the testing could be especially effective. Moving from discovery to offering a range of options for improving the situation is an essential component, though the options could include direct intervention; shared responsibility for referral to another adult (perhaps a parent); or empowering and preparing the young person to do this alone. The direct language designed into the model is part of the means of success. Straying too far from this risks alienating the young person and closing down the conversation (**204**).

It is clear that the model was perceived as being useful by young people and professionals. However, it is important to reflect on the longevity of the project and the funding surrounding it. The funding for this project was received from NHS England (North). The pragmatic way in which that organisation funded the co-designed project allowed the team to work freely with children and young people over the course of a number of months. That project funding did not include continuation funding for dissemination or website maintenance over the months and years following publication of the results in the *Not Just a Thought…* report. Although the website is live and contains all the outputs of the project, there is no continuation funding to keep it up to date. The children, young people and young adults involved in the project were enthused to stay involved in the dissemination and promotion of the outputs so that they could be

used throughout the NHS and potentially beyond. However, no funding was made available to support this dissemination which means the chance of other NHS and social care organisations implementing the recommendations of the *Not Just a Thought...* project is reduced. My learning from this is that for future projects specific negotiation with the funder to ring-fence ongoing funding within a project budget for longer-term dissemination and implementation at the end of the project is crucial.

Work during the project has demonstrated that project teams engaged in coproduction with young people must be open to the young people being able to cause review of the original concepts of the project if necessary. This reaffirms the shared power in decision making that is important to the integrity of young people's participation (205). The children, young people and young adults, including those with a disability, became co-facilitators on each of the consultation days such they set the rules of engagement for both themselves and the adults. It was at these times that some inequitable aspects of how we communicate with children and young people were laid bare. For example, one of the rules they chose was for adults also to raise their hands when they wanted to speak. These visual indicators of an intent to communicate are adopted mainly in schools and were viewed by the young people as a social leveller. The young people adopted democratic decision-making to come up with the name of the project and the chosen *Not Just a Thought…* had universal support of all of the young people involved in the consultation (3).

Results

Two clear messages arose from the children and young people.

- Ask direct questions. If as a practitioner you are thinking there might be concerns about a child or young person you are seeing, don't just think it – ask it; and
- Think about your presentation. Young people want you to smile at them, to be friendly, to let them know you are ready to hear the thoughts they might want to share.

In addition to core and supplementary questions (available on the *Not Just a Thought...* website⁵ and from the University of Salford Institutional Repository (3)) key things that young people wanted from adults starting conversations with them were identified in addition to what young people say they want adults to think about and what they want emergency departments to pledge to them from their services.

Next Steps

A series of recommendations were made to accompany the materials produced during the *Not Just a Thought…* project as follows.

- The Not Just a Thought... Pledge should be adopted in all health care settings and by all health workers.
- A Not Just a Thought... kitemark for all service provision that is co-produced with children and young people should be developed.

⁵ <u>http://notjustathought.org.uk/</u>

- The Core Questions in the Not Just a Thought... report must be used in conjunction with the website resources to ensure that it is not only what we do, but how we do it, that can make a difference.
- 4. The Not Just a Thought... communication model should be trialled across at least one NHS region and an evaluation should be undertaken to examine its effectiveness from the perspectives of children, young people, their parents and health professionals.
- 5. The potential for the *Not Just a Thought…* communication model to be rolled out to schools via school nurses should be investigated.
- Building on the Not Just a Thought... work, communication models for younger children and those with learning and physical disabilities should be developed.
- 7. The current outputs of the Not Just a Thought... project should be enhanced by including subtitles on videos and film to permit access for those who are hard of hearing or deaf.
- The capacity of virtual reality to engage with children and young people within and outside health settings should be further developed to facilitate their engagement and education.
- The educational needs of health staff to use this model in practice and identify the consequences for resources should a greater number of concerns be identified should be ascertained.

10. The development of an ambassadorial scheme that supports children, young people and young adults who invest their time and expertise in the development of services for their peers should be supported.

The *Not Just a Thought...* pledge has been introduced into North Manchester General Hospital emergency department since the release of the project report, and the outputs of the whole project have been promoted by NHS England's Safeguarding Board. Further funding is required to disseminate other aspects of the project outputs.

This study significantly underpins the advocacy and health themes in this thesis. Not only was it important to ensure that the support was in place to enable the children and young people to steer this project and play a leading role in its design and outcomes, it was also important to facilitate the connections for the young people so that momentum was able to be maintained and the participants were left in no doubt about the importance of their work.

REPORT (4): CHILDREN'S ADVOCACY HOUSE CONSULTATION Background

Although the notion of involving and engaging with children and young people to realise meaningful participation is not new **(24)**, the concept of co-production to design services in true partnership with service users has added momentum to the call for the public to be actively engaged in the design and development of public services. Any failure to 'recognise and support' the 'grass roots' social

economy may lead to isolation, lack of trust and low levels of engagement, in turn leading to ineffective and inefficient services **(206)**.

NHS England (North) commissioned the *CYP*@*Salford* research team (207) to find out from children and young people, their views and opinions on the possible creation of a children's advocacy centre in the North of England. From the start, the children and young people preferred the term "Advocacy House" so this was adopted and it also differentiates this project from the "Advocacy Center" movement in the USA (18, 19).

The consultation also sought to determine how young people could be involved in the co-design and co-production of such an initiative from design to the delivery and evaluation of services provided, if the concept were to be taken forward in the future.

Method

A 'whole class' invitation was sent to two Greater Manchester high schools inviting children and young people to participate in the consultation day. Both schools agreed to participate: from one school a class of Year 9 drama students, and from the other school a class of Year 7 students. Both classes were made up of mixed ability young people including some who had a disability. In total, 56 young people participated in the consultation day. The facilitators for the consultation day – held at the University of Salford campus at MediaCityUK – included people from the university as well as local and national health and social care organisations.

A timetable of events was planned to guide the young people and facilitators throughout the day in 30-minute time slots. The facilitators were there to coach and support the young people such that they could engage in a mutual exchange of knowledge. Ten events were available during the day:

- "I once knew a young person who..." explaining anonymised stories of children and young people with mental health difficulties, bereavement, bullying and abuse to put into context the day
- 2. "Steve: a day in my life" drama
- 3. Bharatanatyam dance
- 4. Messages to the Mayor
- 5. Small groups considering who helped the young people, where they went for help and who they approached for help in a number of scenarios. Topics that were raised by young people included domestic abuse, bullying, internet safety, mental health problems, anxiety and depression, loneliness, caring for children, babies and parents, alcohol and substance misuse, exploitation, abuse and smoking
- 6. Values of the Advocacy House
- 7. Graffiti floor, worries and wishes tree, video diary room
- 8. Developing artwork
- 9. Questions to the Mayor and a local Member of Parliament
- 10. A plenary session

Regulated professionals were available throughout the day to deal with any potential safeguarding issues that were raised and the school's teachers, all of whom had undergone safeguarding training, were able to pick up any issues raised back at the school.

Audio and video-recorded data was converted to text manually (with additional field notes for video data). These were themed along with the items communicated on the 'wishes and worry tree', the views expressed on the graffiti floor, the art work and comments from the Twitter[©] Storify[™] as well as any other insights received from the young people during the consultation day **(4)**.

Limitations And Critical Reflections

Similar to the learning from the *Not Just a Thought...* (3) project, the Advocacy House consultation was funded by NHS England (North) as one component of the overarching engagement work with children and young people. The running of the day, the production of the report, and the follow-up to children and young people was an exemplar of how to run other such events in the future.

However, the difficulty with obtaining funding for a single event, even as part of a programme of engagement, was that aside from the production costs of the report no funding was made available for dissemination and future engagement. Although work has been undertaken at the University of Salford and by partner organisations since the consultation event, this has been hampered by lack of funding. This is not inconsistent with other international evidence highlighting that funding can be a barrier to dissemination **(208, 209)**.

Results

Many of the young people used the term 'helping' to convey what they thought an Advocacy House could provide. There was considerable agreement among the young people that an Advocacy House would benefit children and young people. Thematic analysis of the circumstances in which an Advocacy House may be needed included three main issues in relation to this.

- My worries safety, mental health and anxiety
- Worrying about others
- The good and the not so good: hospital experiences

The young people conveyed sophisticated understanding of the need for an Advocacy House to be accessible to children where most children spend their time – in school, but also accessible at times of need such as out-of-hours or during holiday periods. This is consistent with concern that has been raised, for example, during the SARS-CoV-2 COVID-19 pandemic that children who may have been safe at school may no longer be safe when forced to self-isolate and maintain social distancing in an abusive environment which may not be known to statutory services **(185)**.

The young people described an Advocacy House that would be fun, full of happy children, but also a space to be quiet when they needed that calmness. A variety of options were put forward by the young people for the location of the Advocacy House including a mobile centre in a bus. One young person expressed the view that the advocacy centre could help children to be happy.

The adults present tended to focus on the urgent need for an Advocacy House to deal with unmet need, however concern was raised about whether funding for such a centre could be found, and whether the consultation event would become little more than a tick-box exercise. In the time since the event it certainly has been a struggle to identify funding, however members of the team – even two years after the event – continue to raise the principles with key policymakers in an attempt to identify hitherto unknown sources of potential funding.

Conclusions

The young people were able to envision an Advocacy House that would help children and young people in need, and both the young people and adults were enthusiastic and convinced of the need for such a house. Such a resource could go some way to meet current unmet needs which, if left unmet, may have enduring consequences for adult life and the future of the community **(4)**. This study links closely with the advocacy theme in this thesis although the young people who took part in the consultation also raised matters which relate to law (and their protection from abuse) as well as promoting their health.

PAPER (5): DEFINING SIGNIFICANT ILLNESS AND INJURY IN THE EMERGENCY DEPARTMENT

Background

The need to verify whether scoring systems are able to accurately predict severe illness or injury in the emergency department (ED) has been highlighted as one of the top research priorities for paediatric emergency medicine (PEM) in

the UK and Ireland **(73)**. First, there is a need to define significant childhood illness and injury in the ED in order to facilitate quality research in children's emergency medicine **(5)**.

A list of significant illness definitions, which has been used as a benchmark to assess the performance of children's early warning scores, has been created (78), however it is unknown whether this is reflective of a broader group of expert opinion. Prior to the publication of our research there was no agreed or standardised list of significant paediatric conditions, illnesses or injuries in existence, against which the efficacy of children's early warning scores and systems could be measured.

Method

An online, three-round Delphi survey of paediatric emergency medicine, general paediatric, and emergency medicine consultants in the UK and Ireland was conducted. The study was led by Paediatric Emergency Research in the UK and Ireland (PERUKI) in association with General and Adolescent Paediatric Research in the UK and Ireland (GAPRUKI). PERUKI is a collaborative children's emergency medicine research network whose membership at the time consisted of 53 emergency departments. GAPRUKI had 27 sites, 17 of which overlapped with PERUKI **(5)**.

We adopted a modified Delphi process **(145)** whereby after each round, the statements that achieved consensus were eliminated, and statements that did not achieve consensus carried through to the next round of questioning. This approach was taken to maximise participation in the study through minimising

responder fatigue and is an established mode of conducting a consensus-based Delphi (5).

Participants were given a list of clinical conditions based on earlier work **(78)** and asked whether they agreed that each individual condition was significant enough to warrant acute admission to hospital, using a five-point Likert scale ranging from 1 (strong disagree) to 5 (strongly agree). The Delphi process was modified in rounds two and three to address outstanding items from the previous round on which consensus was not achieved in relation to an individual condition.

Limitations And Critical Reflections

The majority of responders in this study were based in emergency care however most participants (65.2%) came from a paediatric background meaning that the bulk of opinion was formed by professionals specifically trained in paediatrics rather than generic emergency medicine. Most respondents were from tertiary centres and this means that the results may not be representative of opinion from non-tertiary centres where resources and management pathways may differ.

All of the PERUKI and GAPRUKI sites in the UK and Ireland were invited to participate, with a 68% response rate. Colleagues who were not affiliated specifically to PERUKI or GAPRUKI were not excluded, which adds to the representativeness of the sample.

Each round saw a predictable reduction in the number of sites responding: demonstration of responder fatigue. The process of rephrasing round one statements not reaching consensus achieved consensus on a further 33 statements in round two, and consensus on an additional four statements in round three. Adding the answer option in round two of 'I do not look after children with this condition' resulted in two conditions reaching consensus in round two that would not have reached the 80% threshold for consensus had the new response option not been available **(5)**.

The primary aim of this research was to develop a set of measures to act as a tool for future research purposes, such as the validation of early warning scores and systems in the emergency department. This list was not designed or validated to provide clinical guidance or be used to judge the quality of care between hospitals. Respondents were informed that the list was to be established for research purposes, so it is possible that different responses and consensus could have resulted had specific clinical issues been emphasised instead **(5)**. It was acknowledged in the paper that the list of conditions which were determined as warranting admission was based on expert opinion.

Results

Round one began with 161 statements. Round two consisted of 83 statements of which 23 were new statements suggested by round one respondents. Round three consisted of 14 statements which all originated from the 11 new statements in round two that did not achieve consensus. Across all three rounds, 154 conditions reached ≥80% positive consensus and one condition (new presentation of uncomplicated Henoch-Schönlein purpura) reached

≥80% negative consensus. The level of expert agreement (of ≥80%) is above most baselines set in the literature (143-145). Consensus was not reached in 37 conditions.

Conclusions

This study's greatest achievement is the creation of a standardised list of statements that have been agreed by a consensus of expert opinion. A list of 154 paediatric illnesses and injuries warranting acute admission to hospital from the emergency department has been established. This robust list can now be used to investigate the performance of children's early warning scores and systems, linking directly to other papers underpinning this thesis, and other child patient safety initiatives in the UK and Ireland, and potentially other countries with similar healthcare settings.

PAPER (6): DIAGNOSTIC ACCURACY OF PAT-POPS AND MANCHEWS FOR ADMISSIONS OF CHILDREN FROM THE EMERGENCY DEPARTMENT Background

Health professionals make judgements on whether children attending emergency departments require hospitalisation or can safely be sent home. These judgements require a complex assessment of the child's health and an estimation of the potential for improvement or deterioration. Since at least 2006 it has been recommended that early identification systems to recognise children developing critical illness should be used **(61)**.

Many children's early warning scores use track and trigger systems, relying on repeated observations over time, intended for use with hospitalised children **(62-64)** to predict which children are likely to deteriorate, rather than who requires admission or discharge from an emergency department. In the absence of a validated emergency department children's early warning score we compared ManChEWS (a track and trigger system) **(64)** with a newly created, bespoke emergency medicine children's early warning score developed by our clinical team (PAT-POPS) **(160)**.

Method

The study population was children aged under 16 years of age attending the emergency department of a district general hospital in the North West of England. Children who left the ED before they could be assessed for admission, or where insufficient data were available to calculate PAT-POPS and ManChEWS, were excluded.

Before the study, nursing staff were trained in the use of PAT-POPS. They were already familiar with ManChEWS. Patient data for the PAT-POPS and ManChEWS assessment were collected prior to the admission decision, so there was blinding to the outcome. A record of the diagnosis and whether the patient was admitted or discharged was also made.

The age, gender and diagnosis of the sample of patients were reported using descriptive statistics. The sensitivity and specificity of PAT-POPS and ManChEWS to predict admission was calculated and presented as comparative ROC curves. The positive and negative likelihood ratios at different cut points of

PAT-POPS and ManChEWS were reported with 95% confidence intervals and p values when appropriate. The calculations were made for separate groups of children with illness or trauma.

Limitations And Critical Reflections

This was a single-centre study and it is possible, that the results could have been different in another centre with an alternative arrangement of services and a different admission threshold. The outcome measure used in this study was whether the child was admitted to hospital as assessed by a clinician working in emergency medicine. Attempts were made to increase the robustness of that measure by including any readmissions within 72 hours of first presentation. In future studies consideration should be given to level of inpatient care (for example ward or high dependency or intensive care), admissions to other hospitals and length of stay in hospital.

Decision-making on a heterogeneous population of medical and trauma patients differs widely. There are some conditions which automatically trigger an admission regardless of the early warning score (such as deliberate self-harm, child protection cases, or a child with a fracture requiring operative management). These cases would exert a particular effect on the results and might be excluded or controlled for in future research.

This study was based on patients who attended the emergency department during a one-month period (March). Diagnoses in paediatrics are subject to seasonal variation, with higher rates of respiratory conditions in winter and higher rates of minor trauma in summer. March was chosen since this was the best time in the year for nurses to be released from their other duties. It was recognised that in future studies sampling patients from throughout the year will be important and this is something which has been incorporated into the subsequent NIHR study described in this thesis (7). Some did not have PAT-POPS recorded because of missing data used to calculate the score. This could not be calculated retrospectively because PAT-POPS includes subjective nurse assessments of the child's behaviour and condition which is not captured routinely.

The mean PAT-POPS score was 0.9 on a scale of 0–18 which could indicate that some of the items used to calculate the score may not be especially relevant, particularly at the lower end of the scale. Future work should investigate the weighted contributions of each of the components of PAT-POPS to the total score and whether some components could be modified or removed without detriment to the sensitivity and specificity reported in this study. This was done in the subsequent NIHR study (7). This initial study was undertaken as a service evaluation of a new tool. Refinement and validation of PAT-POPS was recommended to ensure the various components in the score are combined together to make the most effective tool (6).

Although the results of this study showed that PAT-POPS appeared to be slightly better than ManChEWS at predicting admission of children from the emergency department, scores were disadvantaged by nurses being less familiar with the PAT-POPS tool at the time of the data collection, and hence more likely to make errors in scoring. Furthermore, clinicians were not blinded to the ManChEWS score since this was already in routine use. It is important to

acknowledge that the differences between the two scoring systems while showing *statistical* significance may not imply *clinical* significance (6).

Results

Scores were identified in degree of urgency or need for admission on a red, amber, green scale. A red ManChEWS score identified around 16% of those who were admitted, and successfully identified almost all of those who were not admitted. An amber or red score identified almost 60% of those who were admitted, and 73% of those who were discharged from the emergency department. Children with a red ManChEWS score were almost six times as likely to be admitted, compared with children assessed as green or amber.

A PAT-POPS score of nine or above correctly identified all of those who were sent home, but this cut-off level had poor sensitivity. Sensitivity improved as the cut point lowered, without great loss of specificity until under a score of two. A PAT-POPS score of two or more successfully identified 50% of those who were admitted, and 85% of those who were sent home. The positive likelihood ratios showed that children with a PAT-POPS cut point of two or more were more than three times as likely to be admitted as children with zero or one. The area under the ROC curve for ManChEWS was 0.67 (95% CI 0.64 to 0.70) and for PAT-POPS was 0.72 (95% CI 0.68 to 0.75). The difference was statistically significant (p<0.01).

Conclusions

This study demonstrated that among children aged 0 to 16 years, PAT-POPS has slightly higher diagnostic accuracy for predicting the likelihood of admission

than ManChEWS, and that it can be used for patients with either trauma or illness. Replacing ManChEWS with PAT-POPS would appear to be clinically appropriate in a children's emergency department. The conclusions of this study (6) needed validation in a multicentre study. They formed a firm basis for future work to refine and test the diagnostic accuracy of PAT-POPS (7).

PAPER (7): REFINING AND TESTING THE ACCURACY OF PAT-POPS TO PREDICT ADMISSION AND DISCHARGE OF CHILDREN AND YOUNG PEOPLE WHO ATTEND AN EMERGENCY DEPARTMENT

Background

A review of the use of nine paediatric early warning scores in emergency departments determined they were of only poor-to-moderate use in the prediction of admission (210). A risk-averse strategy of referring all children of 'potential concern' to inpatient paediatric services overloads an already stretched system and leads to unnecessary hospital admissions. There are a limited number of studies on the use of specific scoring systems in children's emergency departments and other urgent care settings.

The initial PAT-POPS study demonstrated an increased relative risk of admission with a PAT-POPS of > 2, and demonstrated the utility of its novel nurse subjective judgement component (211). Further data on over 20,000 patients has demonstrated a relationship between length of stay and increasing POPS score (212). POPS has been shown to be beneficial in defining appropriate admission and also effective in defining safe discharge (80, 211-213).

The aim of the study was to refine and improve the diagnostic accuracy of PAT-POPS by considering what other variables could be included, and, following data analysis to ascertain what contribution each component was making to the admission decision, by weighting individual components. Further, an additional aim was to validate the improved PAT-POPS by repeating the assessments of diagnostic accuracy in an independent dataset. Improving the performance of PAT-POPS could have five benefits:

- More effective identification of children and young people who need to be admitted to hospital and are more likely to be sicker than those who can be discharged;
- 2. Faster identification more reliable prioritisation of children who require urgent review by a senior medical practitioner;
- Improved time to recognition of serious illnesses including, for example, sepsis;
- 4. More effective identification of children who ought to be well enough to be referred back to primary care or self-care at home; and/or
- Additional effects on service efficiency, patient safety, and experiences of care by children attending emergency departments and urgent care facilities.

At the time of writing this thesis the data collection and data analysis component of this study had been completed and submission of a journal article for publication was imminent. The protocol for this study has been published with open access and is submitted as one of the core papers supporting this thesis (7).

Method

A published protocol is available **(7)** and for the purposes of this thesis it is necessary to only summarise the methods used. The results of the study, including full details of the methods used, will be submitted for publication in 2020 and it is the already-published protocol that is relied upon as a core published work underpinning this thesis.

The study population was recruited consecutively. Data collection was prospective over a whole year (1 March 2018 to 28 February 2019) to avoid the effects of bias from seasonal variability which we reported in the earlier study **(6)**. The eligibility criteria were children and young people 0-16 years who attended one of three hospital sites within one NHS trust in Greater Manchester, UK. Children were excluded if they opted out of the study, were brought to the ED following their death in the community or arrived in cardiac arrest when the heart rate and respiratory rate would be unmeasurable. A patient was defined as being admitted to hospital if they left the emergency department to enter the hospital, (including observation and assessment unit or hospital ward), either on first presentation or with the same complaint within seven days of first presentation.

All of the variables in the PAT-POPS tool plus additional variables included in adult scores were considered for inclusion in the new PAT-POPS (version 2) tool. Other data collection included reason for attendance at the emergency

department, diagnosis, deaths in the emergency department, children leaving the department before an admission decision was made, children's characteristics (age, gender and ethnicity), investigated deaths and serious incidents.

Children from one hospital site were utilised for the model development. Logistic regression models were developed with hospital admission as the outcome and including all candidate variables. Variables were removed from the model if they presented a non-significant (p>0.10) contribution.

The calibration score and calibration slope were examined to assess how well the predictions from the model matched the data, and plots were used to compare calibration between injury and illness. The output of stages one and two was the PAT-POPS version 2 score which predicts hospital admission, and the relative weight of each item in the prediction. We undertook two external validations at two other hospitals in Greater Manchester.

The parameters from the multivariable model were used to assign integer points to the level of each risk factor and produce a reference table of risk to develop a clinically useful score, following established guidelines. By applying the points scores to the development dataset, it was possible to calculate the sensitivity, specificity, positive and negative likelihood ratios of PAT-POPS version 2 tool (index test) in predicting admission (reference test) with 95% confidence intervals.

A meeting took place to examine the statistical data, and agree which cut points of the PAT-POPS version 2 score were most suitable to predict (i) safe admission decision and (ii) safe discharge decision, including consideration of what weight to give to sensitivity and specificity in making the decision. The full research team, together with paediatric ED clinicians and an independent methodologist were invited to attend. The usefulness of the PAT-POPS version 2 tool was assessed by calculating the sensitivity, specificity, positive and negative likelihood ratios at the chosen cut-points, to predict admission and discharge. Sub-group analysis took place, comparing the ability of PAT-POPS version 2 to predict admission and discharge in children with injury or illness.

Limitations And Critical Reflections

Overall this was the highest recruiting NIHR study in 2018-2019 and the highest recruiting children's study ever in the history of the NIHR clinical research network. In total 44501 patients were recruited using an opt-out method of recruitment. The study was run in one NHS trust in England, with three separate emergency departments and an urgent care centre. The admission rate varied between the departments from 6% to 32%. One of the significant limitations of the study is that it is not known how the new PAT-POPS version 2 tool would operate in another hospital with, for example, an admission rate of 15%, or 20% or 25%. However, one of the reassuring features of the tool which will be launched as a result of this study is that the model was developed at the site with an admission rate of 32% and then tested using data from the sites with lower admission rates (6% and 8%) and the sensitivity and specificity of the tool

were favourable at these validation sites compared with the model generation site.

Opt-out Consent Model

The results and conclusions of this study are yet to be published, so is the paper setting out the protocol that is relied upon to support the thesis. However, there is one aspect of the published protocol that warrants further discussion. In the design of the study a number of consultation events were held with parents whose children had attended an emergency department in the previous 18 months. The findings were used to inform the research design with regards to the approach to parents, ethics permissions, methods of seeking consent, and study outcome measures.

During the pre-study consultation process the parents involved in public engagement supported an opt-out consent strategy. Patients and their families experienced no difference to their service and suffered no additional physical or psychological risk during the study. Parents advising the study design were clear that it would be inappropriate to add unnecessary concern at the point of triage and examination by the more usual opt-in consent process.

All families were provided with a brief information sheet incorporating core details of the study and how to gain additional information or to opt-out of the study. Clinicians in the departments were available to speak to any participant or parent regarding the study. After the triage process had been completed and clinical reassurance given by the triage nurse that the child was at no immediate risk of harm, parents and children were given the choice to opt-out immediately

or to do so later (remotely). Formal ethical approval for this approach was granted by an NHS research ethics committee.

This opt-out consent strategy enabled data to be collected from a huge sample of children through a whole year, and, in effect, enabled the creation of a database of physiological data recorded from children in urgent and emergency care settings which can be interrogated in future research. A version of opt-out consent has been used internationally for a number of years in large medical trials (170, 214) by presuming that non-response to an invitation to participate indicated acceptability of continued communication about the study. It has been found that opting in to a study resulted in a biased sample and lower response rate than opting out (170). Further, opt-out models of consent have been found to be more efficient in emergency care settings (168) and to reverse selection bias regarding seldom-heard groups in healthcare research such as those who are homeless (166).

In a study of antibiotic prescribing and resistance with multiple options to opt-out a recruitment rate of over 85% with only two complaints was achieved, and no difference was identified between participants and those who opted out in terms of age, gender or diagnosis (167). Reduced sampling bias and greater recruitment from opt-out consent has also been reported, noting that only those who are especially unwilling to participate (or disinterested) are likely to opt-out (169).

Trials have been conducted to establish parents' views and behaviour regarding opt-out consent. In an Australian study on vaccine safety surveillance it was

found that parents accepted opt-out consent, most preferring this or no consent in the case of national surveillance of this kind **(215)** and in the USA opt-out consent has also been found to be acceptable to parents **(216)**.

In summary, the opt-out consent model used in this study and co-designed with parents has enabled the successful recruitment of over 44,500 patients into the research study. A significant database of children's physiology has been created which has enabled the production of a soon-to-be-released PAT-POPS version 2 tool as well as associated research on the interaction between heart rate and temperature, and respiratory rate and temperature.

A key feature of this study, aside from improving child health through pragmatic research in the emergency department was to ensure that data collection was lawful in accordance with the data protection legislation that existed at the time the study commenced and, crucially, to engage constructively with parents in the design of the study so that their views could be articulated in the study's agreed protocol. This is advocacy in action.

5: CONTRIBUTION TO KNOWLEDGE AND THE UNIFYING MODEL

INTRODUCTION

This thesis reports on a voyage of exploration and discovery – a research journey that figuratively and literally led to the publications required for the award of the degree of Doctor of Philosophy **(217)**.

There are three clear components to this thesis which are inextricably linked:

- 1. Research to improve the health of children and young people ("health");
- Making changes to legislation to protect children and young people better ("law"); and
- 3. Advocating with, and on behalf of, children and young people with the aim of protecting their rights and improving their lives ("advocacy").

The *new knowledge* underpinning this thesis has already had impact both in the UK and on a world-wide basis, making a unique contribution to the field of children's advocacy, health and law. In this chapter the demonstrable new knowledge within each of the core publications is summarised together with the collective findings which provide generic learning and contribute directly to the overarching theme of this thesis. In addition, the unifying model which has emerged from this work is explained. This model also has the potential to have impact in and of itself in the future.

LAWS PROTECTING CHILDREN AND YOUNG PEOPLE

Secrecy, complexity of investigation, and absence of prosecutions: the inability to obtain, interpret and exploit data.

In the violence against women and girls strategy 2016-2020 (200), the UK Government has accepted that an approach still needs to be developed in conjunction with the National Police Chiefs' Council for collection of data recorded by police forces in relation to FGM and that *only consideration* will be given to these data being recorded as part of the annual data return (2, 10).

For the first time since the introduction of the 2015 FGM legislation, the study on mandatory reporting of FGM demonstrated that the ability of frontline professionals and policymakers to obtain, interpret and use data is affected by the secrecy that surrounds FGM, the complexities of investigation and the absence of a significant number of prosecutions. Police forces are not collecting data or not responding to requests for information on FGM in a consistent fashion. During the period of the data collection for the study, at a national level the ONS and the Home Office aggregated FGM data with other assaults resulting in the value of recording data being lost entirely.

Mandatory recording and mandatory reporting of FGM is currently more symbolic than effective.

The recording of FGM data is not in a format that helps policymakers and professionals to target preventative strategies towards particular age groups and their communities. There is a huge mismatch between FGM data held by

the former Health and Social Care Information Centre (HSCIC) (now NHS Digital) and that held by the police, suggesting that the true scale of FGM in England and Wales is not being properly investigated. In summary, for the first time, it has been shown that mandatory recording and mandatory reporting of FGM is currently more symbolic than effective.

There should be legislative change to prohibit in law any corporal or physical punishment of children.

The internationally accepted principle of protecting children from violence is undermined by domestic legislation which condones family violence in the form of punishment of children. This creates insuperable difficulties for clinicians trying to distinguish between cases in which a child is at risk from abusive caregivers and those in which a caregiver who is otherwise caring experienced a momentary loss of control.

Work underpinning this thesis has contributed new knowledge to show that the continuation of a defence of lawful chastisement (reasonable punishment) allows for the abuse of children to remain hidden. Recommendations are made for legislative change in the UK, Australia and the USA to give children the same legal protection from assault that provided for adults.

The publication on physical punishment of children has been a key contributor to the argument that the defence of "reasonable punishment" should be removed from UK law, and that in other jurisdictions ratification of international instruments should take place, and that there should be legislative change to prohibit in law any corporal or physical punishment of children. While legislation has been introduced purportedly to protect girls from FGM, UK legislation still does not fully protect children from harm despite the requirements of the UNCRC (**31**). Research has been reported in this thesis regarding the new legislative changes required to provide equal protection to children as to adults (**1**). Fifty-eight states around the world have already reformed their laws to prohibit all corporal punishment of children in all settings, including the home (**218**). As the trend moves towards abolition, it is not an acceptable position for the UK, the USA and Australia to remain missing from that list, notwithstanding that Scotland and Wales, following publication of the study described in this thesis, made the necessary legislative change.

For as long as these countries remain missing from the list of states which prohibit by law the physical punishment of children, effectively children are allowed to be physically assaulted while adults are protected. For the first time, research underpinning this thesis has compared perspectives from the UK, the USA and Australia to make recommendations for legislative change in all three countries to remove the defence of reasonable chastisement in relation to the punishment of children.

While moves to prevent family violence are progressive, the position of a society in which physical punishment of children is permitted yet child abuse is forbidden is not a tenable one. Reducing the number of cases of child abuse must begin with a clear message from society that physical punishment of children, whatever the circumstances, is unacceptable. The situation is serious enough to introduce aspirational legislation to remove justifications for physical punishment of children with the aim of modifying behaviour within society.

CHILDREN'S ADVOCACY

Living On A Railway Line

In *Living on a Railway Line* (11), which won the 2014 Pol Roger prize from the Winston Churchill Memorial Trust, I set out the evidence gained from a ten week overseas research project in Malaysia, Singapore, Hong Kong, Cambodia and four States in the USA. This publication was launched to mark the 25th anniversary of the signing of the UNCRC (31). Through structured interviews with key policymakers and senior leaders supported by a detailed literature search, I investigated the strategies that could potentially be brought back to the UK to protect children from harm better in the future. Following the publication of *Living on a Railway Line* I launched a registered charity in England and Wales (SicKids) and subsequently published work setting out seven steps to protecting children and young people better (Figure 4) that need to occur at all levels of society on a global basis (9).

Seven steps to protecting children and young people
Improve education
Increase employment and employability
Tackle poverty
Decrease neglect
Focus on improving the health of children
Empower girls and young women; remember boys
Develop ChildSafe communities with children and young people at their hearts

Figure 4: Seven steps to protecting children and young people

A series of legislative and policy changes are required in the UK to protect children's rights and more easily identify those at risk of, or who have suffered from, significant harm.

Living on a Railway Line concluded that the UK should introduce mandatory reporting of child abuse into UK law, and that legislative change should take place in the UK to prohibit physical punishment of children. It demanded a new communication model to identify children at risk of significant harm including exploitation and trafficking more efficiently, and proposed that a child advocacy centre pilot should be launched in the UK. A programme of work followed these conclusions, also described in this thesis. The new knowledge from this is already exerting impact.

Not Just A Thought...

Taking forward the advocacy theme from *Living on a Railway Line* **(11)**, the *Not Just a Thought...* **(3)** project was launched to design a new model of communication to use with children and young people to improve the identification of those at risk of exploitation, trafficking and all forms of abuse.

A new communication model has been developed to identify children and young people at risk of abuse, neglect and adverse physical and mental health.

The outcome of the project was a new set of core questions, described for the first time, and designed to identify children and young people primarily at risk of child sexual exploitation and also a wide range of other concerns including

alcohol and drug use, mental health conditions, and other forms of child abuse (3).

Key principles of conversations between children and young people and professionals have been described and a co-designed pledge to children

and young people has been created for emergency departments to use.

A series of key principles that children want from their conversations with professionals was also described, and a pledge was developed for adoption by clinical units when providing services for children and young people. This has already had impact in the children's emergency department at North Manchester General Hospital where the key standards that children want from a department providing urgent and emergency care have been set out clearly so that children and young people can hold the NHS trust to account to deliver these.

Advocacy House

Following the *Not Just a Thought...* project, NHS England (North) commissioned the *CYP*@*Salford* research team **(207)** to find out from children and young people their views and opinions on the possible creation of a children's advocacy centre (Advocacy House) in the North of England **(4)**.

Describing the meaning of advocacy to children and young people.

For the first time the meaning of advocacy for the young people involved in the project was described as well as in what circumstances advocacy might be needed, what an advocacy house for young people might look like, and the values on which such a service should be founded. There was significant unmet need amongst the children and young people who participated in the project, and it is crucial that implementation of an advocacy house must be subject to robust academic evaluation.

Proposals for a novel children's advocacy house (advocacy centre) have been co-produced with children and young people.

Overall there was enthusiasm for the development of an Advocacy House and participants were convinced of the need for such a facility. The young people demonstrated considerable clarity of thought regarding what an Advocacy House might provide, how it might work, and how it might be accessed. A series of six recommendations were made jointly between the young people and the adults for a programme of future work.

PRAGMATIC CHILD HEALTH RESEARCH

Paraldehyde

Assessment of the efficacy of a particular drug within paediatric emergency medicine does not necessarily mandate a randomised controlled trial. Prior to our study **(12)** of the effectiveness and safety of rectal paraldehyde in the management of acute (including prolonged) tonic-clonic convulsions, there were very limited published data on paraldehyde's effectiveness and safety. Previous data focused on paraldehyde's intramuscular route of administration.

Unique evidence of the effectiveness and safety of paraldehyde in treating acute and prolonged tonic-clonic convulsions in children resulted.

For the first time the paraldehyde study provides unique evidence that rectal paraldehyde is effective and safe in treating acute and prolonged tonic-clonic convulsions. This novel work suggests that paraldehyde should remain a treatment for the management of prolonged tonic-clonic convulsions including convulsive status epilepticus. Indeed, this study has already had impact in that it contributed to the evidence base underpinning the launch of the protocols for treating status epilepticus in children by the National Institute for Health and Care Excellence (NICE) in 2011 **(219)**.

Significant Childhood Conditions

It is not just medications that can and should be subject to research within emergency medicine. Clarifying whether paediatric early warning scores (PEWS) accurately predict significant illness is a research priority for UK and Ireland paediatric emergency medicine. However, prior to the study on significant childhood conditions a standardised list of significant conditions to benchmark these scores did not exist.

For the first time a list of significant childhood conditions has been compiled.

In the study on defining significant illness and injury amongst children attending emergency departments **(5)** standardised significant illness endpoints were established for use in determining the performance accuracy of PEWS and safety systems in emergency departments, using a consensus of expert opinion

in the UK and Ireland. This will be used as the benchmark endpoint list for future research into PEWS or safety systems performance in emergency departments.

Early Warning Scores And Systems

It is important to have a benchmark for future research in emergency departments in the UK. Increasing attendances by children aged 0-16 years at UK emergency departments challenges patient safety in the NHS. Health professionals are required to make complex judgements on whether children attending urgent and emergency care services can be sent home safely or require admission to hospital. Health regulation bodies have recommended that an early identification system should be developed to recognise children developing critical illness.

PAT-POPS is a more accurate predictor of admission risk of children from the emergency department than ManChEWS. Opt-out consent can be used to recruit huge numbers of children to research studies in urgent and emergency care settings successfully and ethically.

PAT-POPS is a specific emergency department physiological and observational aggregate scoring system, with scores of 0-18. A higher score indicates greater likelihood of admission. ManChEWS **(64)** assesses six physiological observations to create a trigger score, classified as green, amber or red.

For the first time, it has been shown that PAT-POPS is a more accurate predictor of admission risk than ManChEWS (6). Replacing ManChEWS with

PAT-POPS would appear to be clinically appropriate in a paediatric emergency department. Consequent research to revise and improve the existing tool and determine its utility in determining safe admission and discharge decision making will be reported soon. That study has shown that opt-out consent can be used to recruit huge numbers of children to research studies in urgent and emergency care settings (7).

THE UNIFYING MODEL

This thesis sets out the aims and nature of the publications submitted; the wider perspectives including how each publication fits with current thinking in the area of children's advocacy, health and law; the inter-relationship between the material published; and the main contribution to knowledge that the works bring.

Advocating for children and young people can result in improved health outcomes for children and legislation which protects them. Legislation can result in better health outcomes by setting out what is lawful and what is unlawful, with the emphasis on avoiding the unlawful so that aspects of a child's life, including their health, are not compromised **(Figure 5)**.

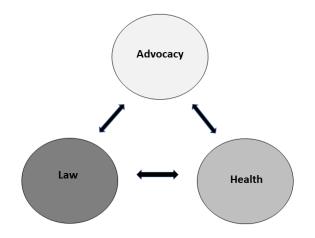


Figure 5: Children's Law, Advocacy and Health

It is by having a rounded approach and focusing on multiple areas of research in the linked topics of children's advocacy, health and law that outcomes for children and young people have a greater chance of being improved **(Figure 6)**.

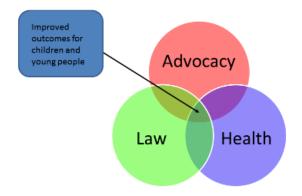


Figure 6: Improving outcomes for children and young people

Laws, whether in statute or in common law, underpin a society and everyone who lives within it. They represent the foundation of what is lawful and unlawful in society and are formed by legislatures considering the views of the society who will, ultimately, be bound by those laws. That society can take many forms:

- 1. A local community;
- 2. A country;
- 3. A region (for example, the European Union); or
- 4. Global (international law).

Professionals can advocate for, and with, children and young people at an individual level (to protect the individual rights of an individual child) or a societal level (advocating to promote and protect children's rights in general). Child health can be improved at a micro-level (an individual child or small numbers of children) or a macro (societal) level **(Figure 7)**.

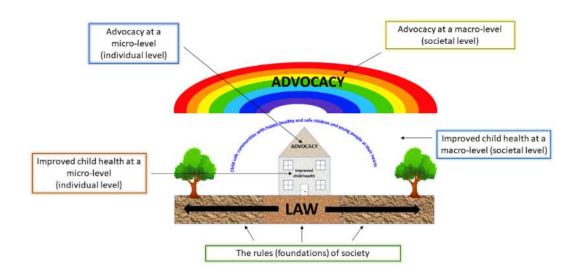


Figure 7: Micro- and Macro-Advocacy

Ensuring the best possible outcome for children and young people requires us all to do everything possible to create and promote communities with integrated and optimised health and social wellbeing in which children and young people can develop and flourish: happily, healthily and safe from harm. It is only when the laws in a society properly protect children and young people, there is advocacy on a micro- and macro-basis by healthcare professionals and members of the community, and there is a focus on child-health at micro- and macro-level, that truly child-safe communities with children and young people at their hearts can be created.

That is the theme that the cohesive body of work in this thesis demonstrates as it can be visually represented as shown in **Figure 8**. Those communities in which this model operates will have integrated and optimised health and social wellbeing as a core component.

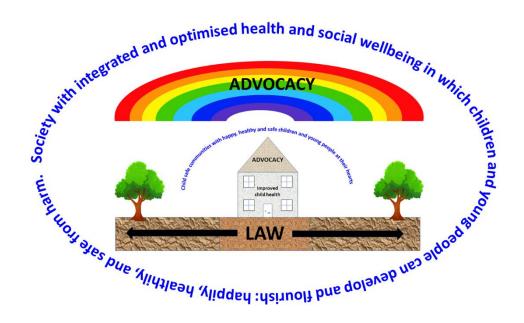


Figure 8: Integrated children's health and social wellbeing

6: KEY MESSAGES AND IMPACT

MESSAGES FOR RESEARCH AND SOCIETY

In the light of the new knowledge described in this thesis there are key messages arising for research and society – be that in the UK or in our Global Society. Those key messages are summarised in this chapter together with the impact already exerted by the contributing studies.

Female Genital Mutilation

- 1. FGM data must be recorded as part of the annual data return.
- 2. At a police force / police authority, Local Authority and national level FGM data must not be aggregated with other assaults as this results in the value of recording data being lost entirely.
- 3. NHS FGM data should be collected against the same criteria as police data.
- 4. Aggregate national data on FGM should be collected by a central authority, led by an FGM Commissioner.
- 5. Further guidance is needed by police forces on responding to sensitive requests under the Freedom of Information Act 2000.
- 6. Mandatory recording and mandatory reporting of FGM is currently more symbolic than effective: a situation that must change.

Physical Punishment Of Children

- 7. The internationally accepted principle of protecting children from violence is undermined by domestic legislation which permits punishment of children.
- 8. All countries around the world should legislate to prohibit physical punishment of children in all circumstances and this should be accompanied by a public information and education campaign about alternatives to physical punishment.

Legislative Change Required

9. The UK should introduce mandatory reporting of child abuse into UK law, and a full academic evaluation of that new law is required.

Children's Advocacy

- 10. A child advocacy centre pilot should be launched in the UK.
- 11. The *Not Just a Thought...* communication model should be used by professionals communicating with children and young people.
- 12. The *Not Just a Thought...* pledge should be used by departments providing urgent and emergency care to children to set out clearly the key standards that children can expect from that department.

Emergency Child Health

- 13. Paraldehyde should remain a treatment for the management of prolonged tonic-clonic convulsions including convulsive status epilepticus.
- 14. Future research into children's early warning scores or safety systems in emergency departments should use, as a benchmark, the list of significant childhood conditions developed as part of the work underpinning this thesis.
- 15. PAT-POPS is a more accurate predictor of admission risk than ManChEWS and it may be appropriate to withdraw ManChEWS from use in EDs and replace this with PAT-POPS. However, in 2020 the results of the largest ever children's research study in the history of the NIHR Clinical Research Network will be launched (7) – this will be a new early warning score model with better sensitivity and specificity than PAT-POPS or ManChEWS, therefore organisations may wish to wait until later in 2020 before considering whether they wish to implement PAT-POPS or, in the alternative, the new score soon to be announced as a result of work described in this thesis.
- 16. Opt-out consent models can be used to successfully and ethically recruit huge numbers of children to research studies in EDs.

IMPACT

This thesis is founded upon a compendium of core and supplementary published works. In addition to the published works themselves, over the period April 2014 to October 2019 there have been a number of examples of how research and projects that are related to the underpinning published works in this thesis have advanced. Those impacts have all been described in *Life on the tracks* (8). However, some of the key impacts which are directly related to the core and supplementary publications are highlighted here. I believe that those impacts, and the work that underpins them, mirror Sir Winston Churchill's encouragement to all people that they can make the best use of their own life by doing everything possible to make our world a better place for future generations.

Launch Of A New Charity (SicKids)

In 2015 I launched, and now chair the Board of Trustees of, a registered charity in England and Wales (SicKids) **(220)** which now works between the North West of England and Cambodia. The main areas of focus of SicKids have been to provide sensory spaces which can be used by disabled children or those who are scared of being in a healthcare environment; to deliver outreach medical support to vulnerable children living in Cambodia; and to develop skills and experience amongst health care professionals. Children with either a physical disability or a learning disability are more likely to suffer from abuse than those children who are not disabled **(221)**.

SicKids' first sensory space was opened in Manchester (222) by Her Excellency Dr Rathchavy Soeung, the Cambodian Ambassador to the UK, and Mr Barry Dixon DL. This sensory space has since been recognised as an outstanding facility by the Care Quality Commission (223). Since that time the Care Quality Commission has also recognised the SicKids sensory space in the emergency department of the Royal Oldham Hospital as an example of "Outstanding Practice".

Since the first sensory space opened, SicKids has installed a series of further sensory spaces and as a result this work, over 30,000 children in North Manchester, over 25,000 children in Oldham and over 25,000 children in Salford all now have access to a bespoke sensory space within their local emergency departments at North Manchester General Hospital, The Royal Oldham Hospital and Salford Royal Hospital. In Cambodia, over 5000 children and their families in Sihanoukville and all of the children in the catchment area of Battambang Referral Hospital in Northern Cambodia now have access to modern sensory spaces for the first time.

Work in Cambodia has also included engaging with Friends International to develop proposals to modify the ChildSafe movement principles (224), originating in South East Asia, for use in the UK, in collaboration with colleagues at the University of Salford.

British Medical Association Policy On Safeguarding Vulnerable Children As a direct result of the launch of *Living on a Railway Line* **(11)** the British Medical Association (BMA), which represents 169,000 doctors and 19,000

medical students in the UK, changed its national policy on safeguarding vulnerable children **(225)** following a motion I presented to the Annual Representative Meeting in 2015. The BMA adopts a policy-based non-political approach such that policy is set at the Annual Representative Meeting and it then translates into all the work of the BMA going forwards.

World Medical Association Policy On Child Abuse And Neglect

The World Medical Association (WMA) represents 112 countries around the world and over 10 million physicians. Following the BMA updating its policy on safeguarding vulnerable children, I led a programme of work within the BMA aiming to encourage the WMA to update its policy on child abuse. As a direct result of work within *Living on a Railway Line* (11) the WMA updated its policy statement on child abuse and neglect (226) in late 2017 at a meeting in Chicago, following proposals put to it by the BMA. This new policy on child abuse and neglect is now available to national medical associations around the world and over 10 million physicians worldwide.

International Standards Of Care For Children In EDs

The International Federation for Emergency Medicine (IFEM) was founded in 1989 with the purpose of promoting access to, and leading the development of, the highest quality of emergency medical care for all people worldwide. I was asked to rewrite the Safeguarding Vulnerable Children chapter **(227)** in the IFEM's guidance on standards for children in emergency departments.

The BMA policy and the WMA statement were instrumental in enabling me to write guidance which now forms part of an international publication which will

assist hospitals around the world by defining the minimum standards of care for children aged 0-18 years who attend emergency departments.

ChildSafe Accreditation

As a direct result of the launch of *Living on a Railway Line* (11) the University of Salford has become the first university in the world to be accredited under the ChildSafe[®] programme (228) underlining the importance of giving everyone a way to protect children in the future. ChildSafe works to protect children and young people by raising awareness of the ways in which their international rights are being compromised, and equipping members of the community, and institutions, to act in the best interests of children to restore their rights. Through a programme of awareness raising, behaviour change, advocacy, child protection training, and emergency hotlines, the ChildSafe programme works to improve child rights.

Partnership Working In Cambodia

Soon after my Fellowship findings were released, I led The Pennine Acute Hospitals NHS Trust and the University of Salford to launch a partnership to improve the health and wellbeing of Cambodian street- and beach-living and associated vulnerable children **(229, 230)**.

Often in partnership with SicKids, the programme of work that has been undertaken since 2015 **(9)** has demonstrated quality improvements for the benefit of children and young people, including the production of a children's asthma guideline for the first time. The local team believes that this guideline has had an enormously positive effect on children in the community such that their asthma symptoms are now under significantly better control. Very few children attend the clinic now with acute exacerbations of asthma as they are more easily managed in the community through ongoing treatment and symptom prevention. In addition, guidelines for adult hypertension and type II diabetes mellitus have been introduced for the first time, and a multi-disciplinary child development team has conducted reviews of disabled children for the first time in what we believe to be South West Cambodia's first truly multiprofessional child development clinic arrangement. That team continues to provide virtual support via video conferencing from the UK.

7: FUTURE PLANS

Reflecting on the key messages for research and society, the impact already achieved, and ambition to pursue the original studies and other areas of child health research further, a research plan has been developed. This includes publishing further work in these areas and applying for further research grants to undertake follow-on and new studies in children's law, advocacy, and health.

This chapter details work published after submission of the soft-bound thesis, publications which are currently under review or in-press, research grants that have been submitted since the viva voce examination, proposals for future studies and a personal ambition.

PUBLICATIONS SUBSEQUENT TO THE CORE AND SUPPLEMENTARY PUBLISHED WORKS IN THIS THESIS

Unlocking Children's Voices During the COVID-19 Pandemic Lockdown The SARS-CoV-2 (Coronavirus) COVID-19 pandemic has rapidly become a global phenomenon with hugely significant effects on family life. Although the clinical course of COVID-19 appears to be much milder in children compared with adults, the other consequences of the pandemic are arguably equally, if not more, damaging to children. It is therefore essential that the impact of the coronavirus crisis on the lives of children and young people is understood. Tragically, family members have died. Children have missed out on weeks of inschool education. Social contact between children living in different homes has been decimated. Concerns have arisen about higher levels of abuse.

Since April 2020 members of the public have been able to submit questions to the UK government for the COVID-19 press briefing. Astonishingly, the question-submission rules specifically prohibit questions from children, blatantly ignoring their rights. An attempt by someone under the age of 18 years to submit a question results in an error message: "*sorry you cannot submit a question. You cannot ask a question in the coronavirus (COVID-19) press conference because you're not old enough*". This stance completely devalues the expertise that children have and silences their voices. That any reporter or other adult may pose questions (to be answered to one degree or another) but questions from someone on the day before their 18th birthday will not even be considered, is ludicrous and indefensible.

In our letter to Archives of Disease in Childhood **(231)** it has been possible to lay bare the inequity of the ruling that children cannot be heard. Not allowing children to participate, express their opinions and be heard on matters that affect them is wrong and is a breach of their human rights. If not because it is their right to be heard; if not because it is the right thing to do; then because the future of society depends on engaged, experienced and enthusiastic children becoming engaged, experienced and enthusiastic adults, it is time for children to have their own COVID-19 questions answered by the UK government. That requires a change in policy so that the prohibition of questions from anyone under the age of 18 years is urgently removed. The letter therefore calls upon child health professionals to add to the demand for change to further promote children's rights as the COVID-19 pandemic progresses.

FGM Protection Orders

A mandatory reporting duty for FGM requires regulated health and social care professionals and teachers in England and Wales to report known cases of FGM in under 18-year-olds to the police. An application to the Court for an FGM Protection Order (FGMPO) can be made to keep individual women and girls safe from FGM. In a paper published in the British Journal of Midwifery in July 2020 (127) it has been possible to reveal the significant disconnect between the number of FGMPO applications and known recorded cases of FGM.

Using data obtained via applications made under the provisions set out in the Freedom of Information Act 2000 our research reveals that between April 2015 and September 2019, a total of 45950 attendances to health services occurred in England by individuals who have been identified to have suffered FGM, or where the attendance to services was due to a consequence of suffering FGM.

Between this period a total of 22500 individuals have been recorded to have undergone FGM, although it is not certain when that FGM took place. Family Court data was available for July 2015 to September 2019. During this period a total of 408 applications for FGMPOs were made to the Family Court in England and Wales. From these applications 489 orders were made. The disparity between these statistics is due to occasions where multiple orders have been granted stemming from a single application. The Crown Prosecution Service (CPS) reported that there were no FGM convictions in 2016-2017 or 2017-2018, however there was one offence charged in 2016-2017 which reached a Magistrates Court Hearing. In the 2018-2019 financial year there were two

defendants prosecuted for FGM, one of whom was convicted and the other acquitted.

The very low levels of applications for FGMPOs may very well indicate a lack of awareness amongst the public and professionals about the legal protection that is available to protect women and girls from FGM, although specific research is required in a new study to understand the exact reasons behind the low number of applications compared with FGM cases.

The introduction of FGMPOs requires critical exploration as there is insufficient evidence to show that FGMPOs are effective in protecting women and girls from FGM. It is therefore unclear what impact, if any, FGMPOs are having upon the protection of women and girls at risk of FGM. The barriers to the implementation of FGMPOs and possible solutions are discussed in the paper as well as proposals made for the appointment of a national FGM Commissioner to lead public health initiatives to prevent FGM, to coordinate data collection and to commission a full academic evaluation of FGM law in the UK.

PUBLICATIONS UNDER REVIEW OR IN-PRESS

Opt-out Consent In Children's Emergency Medicine

The use of opt-out consent has been recognised as a valid and ethical means of recruiting participants to studies particularly with large samples and where the risk to participants is small. However, it is sometimes misunderstood and can be a problematic factor in gaining research ethics committee approval. In a large study of 44,501 cases of children attending one of three emergency or urgent care departments (7), opt-out consent was used with considerable

success. In a paper reviewing the status of opt-out consent, the factors that made this effective for this study, but also more recent concerns which may make opt-out consent no longer acceptable, are explored. This qualitative paper – exploring arguments for and against opt-out consent – is currently under review.

Inter-rater reliability of emergency assessments of vital signs and clinical features of children: direct observation method

The PAT-POPS version 2 tool (substantive paper currently under review, including the new name which is currently embargoed pending publication) is an assessment tool that helps to predict hospital admission using components including patient characteristics, vital signs (heart rate, temperature, respiratory rate, oxygen saturation) and clinical features (e.g. work of breathing, behaviour, nurse judgement). It aims to assist in safe admission and discharge decision making in environments such as emergency departments and urgent care centres. Determining the inter-rater reliability of scoring tools such as the PAT-POPS version 2 tool, which are used in clinical practice, can be difficult. In our paper we determine the inter-rater reliability of six clinical components of the PAT-POPS version 2 tool.

The first rater was the assessing nurse with a research nurse acting as a second rater repeating the process of collecting clinical information on a sample of 90 patients. Two independent measures for each child were compared using kappa or pabak. Inter-rater reliability ranged from moderate to very good for all measurements except nurse judgement for which agreement was fair. Complete information from both raters on all the clinical components of the

PAGE score were available for 73 children (81%). These total scores showed 'good' inter-rater reliability (0.635 [95% confidence intervals 0.519 to 0.688] weighted kappa).

The findings suggest different nurses would demonstrate good inter-rater reliability when collecting acute assessments needed for the PAT-POPS version 2 tool given the same child, reinforcing the applicability of the tool. The importance of determining reliability in scoring systems is highlighted and a suitable methodology presented.

Development Of A Multivariable Prediction Model And Scoring Tool For Identification Of Children In Need Of Hospital Admission From The Emergency Department: the [PAT-POPS Version 2 Tool]

In a paper currently under review the results of our £316,731 NIHR RfPB study are presented as well as the new PAT-POPS version 2 tool described. Using the methods described in published work (7). The paper explains that the PAT-POPS version 2 tool uses routinely-collected data to determine whether children attending an ED or urgent care centre can be safely admitted or discharged. For units without the immediate availability of senior doctors working in paediatric emergency medicine, the paper argues that the PAT-POPS version 2 tool can assist staff to determine risk of admission, with cut-off values being able to be adjusted to local circumstances.

RESEARCH GRANTS SUBMITTED

Music In Children's Emergency Departments (MusIC-ED): An Exploratory Study Following The SARS-CoV-2 (COVID-19) Pandemic

An application has been made to the NIHR RfPB funding stream for just under £150,000 to undertake an exploratory study of a music intervention in children's emergency departments. Taking a child to a hospital emergency department can be stressful for both children and parents. Much work has been done to improve the environment of emergency departments, with play areas and, when possible, creating a separate area for children where they are not exposed to adult patients and their sometimes unacceptable behaviour. A more unusual strategy in hospital wards has been the introduction of live music-making by professional musicians. In this study plans are set out to apply our experience of this to including live music-making in two children's emergency departments.

No-one knows yet whether or not this will work. No-one knows what the best way would be to gauge how well it works. We will try to find these things out in this "feasibility" study. Feasibility means that before we do a much larger study to see if the music-making strategy works, we want to test out each of the components of the study in a smaller project. This means that we can make changes before we do the main research study.

First, we need to see if having musicians in an emergency department is practical for staff and acceptable to families. The musicians might be in the wrong place, or they might disrupt the work of the staff. Families might have a preference for where and when the music is played. The musicians could learn how to balance playing in public areas and in cubicles. We will explore how we can measure or ask about the effect of the music. We will try to measure stress levels in children (with a cheek swab of salivary cortisone) before and after the music is played. We will measure the noise level in different parts of the department with and without music playing. Sometimes the overall level of noise goes down when music is played. We will quietly observe some children's behaviour to see if they show any signs of calming down or being less stressed as a result of the music. We will also just ask families directly what they think about the music and the impact on them.

Finally, we will see how well we could do this sort of study if personal protective clothing were to be needed in future as for COVID-19, together with distancing requirements. A clarinet could not be played through a mask and a visor, for example. We will explore what the problems and potential solutions could be.

This study will use mixed methods (96, 97):

We will measure noise levels continuously from 30 minutes before the music starts to 30 minutes after its conclusion and will compare this with noise levels on days when music is not present. We will simultaneously measure a continuous average level (L_{Aeq} in dB), a background level (L_{A90} in dB) and a near-maximum level (L_{A10} in dB). Measurements will be made in set areas of the department. This will help to determine if and how measurement of noise level can be used in the larger study of the impact of the music intervention and whether or not there is any notable difference;

- We will use survey methods, administered by research nurses, to establish the responses of attending parents and children before they leave the department (a) to their experiences in the emergency department, (b) to the methods used to collect the data, and (c) to the perceived effect of the experiences. This will occur on days when music is and is not present. The research nurses will follow up a sample of children and families via telephone or video call at home to explore in more detail their experiences in the department. We will test the feasibility of following up 10 families within 24 hours of attendance to the ED, 10 within 7 calendar days of attendance, and 10 within 14 calendar days of attendance to enable us to gauge whether immediate or delayed contact works best;
- We will employ an observational schedule based on the Anx-DOS (232) for non-participant observers to record child behaviour for specific signs of stress before the intervention, during the music, and on completion of their visit to the department;
- We will use survey methods, administered and completed by research nurses, to establish the extent to which musicians were able to create bespoke music for the department which could be selected by children, in a post COVID-19 situation (where mask-wearing, social-distancing and other restrictions may still be in place);
- We will use non-invasive techniques (cheek swabs) to determine which is the appropriate swab to use to measure cortisone and see if it is possible to measure and interpret cortisone levels in children attending

the department (on music intervention and control days without music); and

 A consensus meeting will take place to determine what the overall learning is for making music in emergency departments, how musicians learn to adapt their practise in PPE, and what healthcare professionals can learn from this for their future practise.

If the application is successful, this study will commence on 5 July 2021.

Is My Child Sick? Post-COVID-19 Children's Emergency Physiology (CEP) In Urgent Care Settings

An application has been made to the NIHR RfPB funding stream for just under £150,000 to undertake a prospective, observational quantitative study of children's emergency physiology in urgent care settings, with significant patient and public involvement (PPI). When children attend emergency departments and urgent care settings, doctors and other decision-making clinicians make judgments about which children are seriously unwell and require emergency treatment and which have minor illnesses or injuries who do not need any further specialist care.

It is routine for children to have measurements of temperature, heart rate, breathing rate and the amount of oxygen in the blood. These "vital signs" do not require the insertion of needles or probes into the body and are termed "noninvasive". Vital signs are used to make decisions on the urgency of treatment, the severity of a disease and whether investigations and treatments are needed. These decisions are made on whether the child's values differ from what a normal measurement for a child of that age would be (as normal values are dependent on age, for example, a baby at rest normally has a much higher heart rate than a teenager at rest). However, the normal measurements (or "values") for each of these can vary significantly and there is no single figure that represents "normal".

The lack of agreement on what the normal range of values should be can make it difficult to decide whether a child has an apparently abnormal vital sign but is otherwise well, or whether that abnormal vital sign represents a possible serious underlying illness including, for example, sepsis or COVID-19.

A further problem is that abnormalities in vital signs impact on other vital signs. In particular, a raised temperature in a child will increase their heart rate. It can be challenging for staff to make decisions as they struggle to work out if the heart rate is high because of disease or because of their temperature. In this study we will measure heart rate, temperature, breathing rate and amount of oxygen in the blood in a very large number of children, some of whom will be well, and others who will be ill, in order to develop a table of normal measurements (and the link between them for different age groups) and a table of abnormal measurements with the same links.

We will focus on the links between temperature and heart rate, and between temperature and breathing rate, because these are the most important for clinicians to make treatment decisions. Specifically, we will investigate:

- What is the distribution of physiological variables in children aged under 16 years of age in our patient population?
- What is the relationship between temperature and heart rate in children aged under 16 years of age?
- What is the relationship between temperature and respiratory rate in children aged under 16 years of age?

Previous studies have investigated this but have not utilised a large data set in emergency departments and urgent care centres where acutely unwell children commonly attend **(233)**. Previous studies have considered well children in schools or examined children in hospital wards who have already had treatments. The large number of cases in this proposed study will mean that the evidence will be strong, and it will apply across hospitals in the NHS.

Data will be collected at triage by clinical staff as part of routine practice and entered into existing NHS trust electronic systems. Data will be stored securely in these systems and exported to a purpose-designed research database every three months. This allows for internal data cleansing before transmission of the data for analysis, and also provides for any systematic error in either human or automated processes to be identified quickly and rectified.

Age-specific reference intervals for clinical variables (oxygen saturation, heart rate, respiratory rate, temperature and weight) will using established methods of estimating reference intervals, age-specific reference intervals (where the measurement is dependent on a covariate, typically age) and assessing goodness-of-fit **(234)**. The sample size has been designed to allow full years of

recruitment in order to assuage concerns regarding seasonal variation. Given the age distribution of attendees we anticipate that the total of 50,000 participants will include sufficient numbers of the smallest age categories (and sufficient discrimination within the zero to 12 months range in particular) to allow precise estimation of the distributional parameters for each clinical variable.

Graphical exploratory analysis will allow a preliminary look at the direction, shape (linear or otherwise) and magnitude or relationships between the variables of interest. To examine more exactly how temperature is associated with both heart rate and respiratory rate multi-level mixed effects regression model analysis will be used. This will account for the repeated observations at both the site and patient level using fixed and/or random effects as appropriate. If there is suspicion that the relationship between the variables being examined is not linear, this will be able to be investigated more fully by including squared or cubed terms (for example) for these in the model.

Data will be exported anonymously (with no patient identifiable information included) into a database by the Trust's Academic Information Technology Manager, which will then be passed to the statistical team for analysis.

If the application is successful, this study will commence on 5 July 2021.

FUTURE STUDIES

Using similar quantitative methods to those described in published work (7) a research proposal is being developed to devise and test the diagnostic accuracy of a bespoke primary care children's early warning score. In addition,

using a qualitative methodology a study is being devised to establish what impact, if any, a specialist children's bereavement service can have for families affected by the sudden and unexpected death of a child. It is anticipated that these will be ready for submission for consideration by a funder in early 2021.

PERSONAL AMBITION

Children have the right to be heard and the right to healthcare. Children's rights underpin their access to healthcare, their participation in research and their voices being heard at the highest social and political levels, nationally and internationally. Subject to being awarded the degree of Doctor of Philosophy I plan to encourage others to join me in researching the linked areas of child rights law, children's advocacy and child health research with a focus on emergency medicine. I envisage this being a multi-professional, multidisciplinary group, holding a joint curriculum vitae in research grants, publications, doctoral student supervision, and evidence of impact.

I cannot find any evidence of any UK university having already appointed a *Professor of Children's Rights, Law, and Advocacy* (although there are professorial appointments in Education, Law and Children's Rights; and International Children's Rights). I hope to secure this appointment. Such a post would be the foundation of collaborations with academics around the world, attracting further masters-level and doctoral students, and securing research grant funding. At a national level the holder of such a professorial appointment would be a key collaborator with the UK children's commissioners. Internationally, they would provide a valuable contribution to global children's

rights via processes such as the United Nations Human Rights Council Special Procedures⁶.

⁶ https://www.ohchr.org/EN/HRBodies/HRC/Pages/SpecialProcedures.aspx

8: CONCLUSIONS

The published works supporting this thesis demonstrate a clear notion that improving the lives of children and young people, both in the UK and on a global basis, requires a coordinated focus on innovations in the three inextricably linked areas: children's advocacy; pragmatic child health research; and legislation underpinning children's rights.

Legislation and regulations set out in statute and common law collectively describe what is lawful and unlawful. Children's rights need to be promoted and protected, and child health can only be improved to the maximum potential with optimal overarching child welfare. Ensuring the best possible outcome for children and young people requires us all to do everything possible to create and promote communities with integrated and optimised health and social wellbeing in which children and young people can develop and flourish: happily, healthily and safe from harm.

This must involve having legislation in place that properly protects child rights (and professionals have a responsibility to contribute to the development of this legislation); health professionals advocating for children and young people at a local and global level; and health professionals being involved in pragmatic child health research, even if their appointment is not a primarily academic one.

I have completed, and demonstrated in this thesis, a cohesive body of work linking together the topics of children's advocacy, health and law, with demonstrable new knowledge much of which has already had impact. This all

fits together into a model of developing child safe communities with children and young people at their hearts. That novel model, describing the interaction between children's advocacy, health and law in communities where there is integrated and optimised health and social wellbeing as a core component, also has the potential to have impact in the future.

With a clinical, community and research focus on children's advocacy, health and law and if all of those communities have a common aim (to protect children, who are of course the future of the adult members of the global human race), a global society with integrated and optimised health and social wellbeing will be created in which children and young people can develop and flourish: happily, healthily and safe from harm **(Figure 9).**

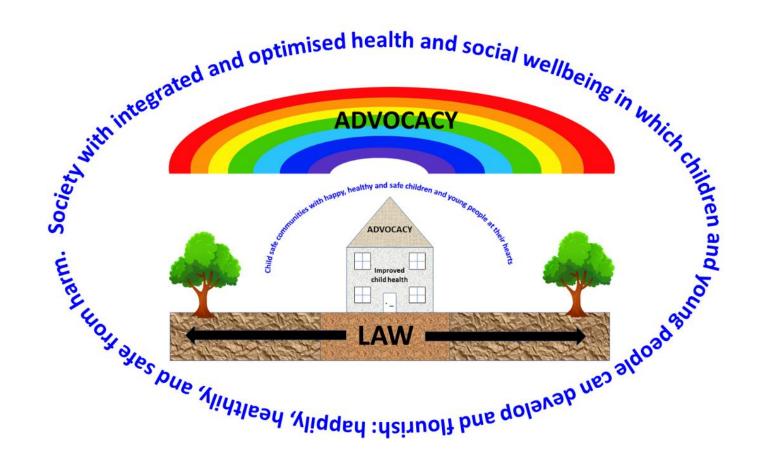


Figure 9: Child safe communities with children and young people at their hearts

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169

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APPENDIX ONE

AUTHORSHIP OF INDIVIDUAL PUBLISHED WORKS

Core Published Work (1)

Physical punishment of children : time to end the defence of reasonable chastisement in the UK, USA and Australia: <u>Andrew Rowland</u> undertook the initial literature review. The chapter, written by <u>Andrew Rowland</u> in his publication *Living on a Railway Line* was used as the initial first draft of the paper. All authors then jointly contributed to manuscript revisions and further literature inclusion as well as approved the final version of the manuscript for publication.

Core Published Work (2)

Mandatory reporting of female genital mutilation in children in the UK: The authorship contributor statement is published within the final published work. All authors agreed to the contents of the manuscript, including the contributor statement, prior to publication and publication would not have been possible without this agreement. <u>Andrew Rowland</u> devised the concept of the study, conducted the Freedom of Information Act 2000 requests (study design and data collection) and is the guarantor of the published paper. Yusuf Malik analysed the results of the literature search and analysed the results of the Freedom of Information.

Core Published Work (3)

Not Just a Thought... A Communication Model: <u>Andrew Rowland</u> had a significant contribution to the writing of the *Not Just a Thought...* report which was 8275 words in length and submitted to the British Library (ISBN: 978-1-912337-06-4), was the Project Director following receipt of a grant from NHS England and jointly contributed to the writing of the manuscript (confirmed by the Project Manager).

Core Published Work (4)

Outcomes from the children and young people's Advocacy House consultation event – MediaCityUK: <u>Andrew Rowland</u> conceived and commissioned the project following receipt of a grant from NHS England, participated actively in the consultation workshop, maintained liaison with external partners (including Members of Parliament) and jointly contributed to the writing of the manuscript.

Core Published Work (5)

Defining significant childhood illness and injury in the Emergency Department – A consensus of UK and Ireland expert opinion: The authorship contributor statement is published within the final published work. All authors agreed to the contents of the manuscript, including the contributor statement, prior to publication and publication would not have been possible without this agreement. <u>Andrew Rowland</u> advised on the study design and analysis and contributed to the write-up of the paper. Ian Maconochie was the project supervisor; conceived the idea for the project; advised on the study design; and contributed to the write-up of the paper. Peter Lillitos was the project lead, responsible for designing the study and conducting the analysis and was the main author of the paper. Mark Lyttle was responsible for disseminating the surveys to the relevant network groups and site leads; advised on the study design and the analysis; and contributed to the write-up of the paper. Colin Powell was involved in disseminating the survey; advised on the study design; and contributed to the write-up of the paper. Damian Roland advised on the study design and analysis and contributed to the write-up of the paper. Julian Sandell advised on the study design and analysis and contributed to the write-up of the paper. Susan Chapman advised on the study design and analysis and contributed to the write-up of the paper.

Core Published Work (6)

Diagnostic accuracy of PAT-POPS and ManChEWS for admissions of children from the Emergency Department: The authorship contributor statement is published within the final published work. All authors agreed to the contents of the manuscript, including the contributor statement, prior to publication and publication would not have been possible without this agreement. <u>Andrew Rowland</u> conceived and led the research project, had substantial input into the writing of the paper and revised the paper in response to reviewer comments. Sarah Cotterill wrote the first draft, undertook the statistical analysis, finalised the manuscript and revised the paper in response to reviewer comments. Jacqueline Kelly co-led the data collection, reviewed the draft manuscript and had substantial input into database design and data entry. Helen Lees co-led the data collection, reviewed the draft manuscript and had substantial input into database design and data entry. Mohammed Kamara

176

facilitated the literature search, contributed to data entry and reviewed the draft manuscript.

Core Published Work (7)

Refining and testing the diagnostic accuracy of an assessment tool (PAT-POPS) to predict admission and discharge of children and young people who attend an Emergency Department: Protocol for an observational study: The authorship contributor statement is published within the final published work. All authors agreed to the contents of the manuscript, including the contributor statement, prior to publication and publication would not have been possible without this agreement. Damian Roland, <u>Andrew Rowland</u>, Sarah Cotterill and Tony Long conceived the idea. Damian Roland, <u>Andrew</u> <u>Rowland</u>, Steve Woby, Joan Livesley, Tony Long, Sarah Cotterill and Calvin Heal each made substantial contributions to the study design. All authors were involved in drafting the manuscript, revising it critically for intellectual content and gave final approval of the version to be published.

Supplementary Published Work (8)

Life on the tracks: This publication is based on <u>Andrew Rowland</u>'s own independent work and, whilst gratefully acknowledging the support of those individuals who have contributed to the projects described within *Life on the tracks*, <u>Andrew Rowland</u> is the sole author of the work.

Supplementary Published Work (9)

From sick kids to SicKids! : The authorship contributor statement is published within the final, published work. All authors agreed to the contents of the

manuscript, including the contributor statement, prior to publication and publication would not have been possible without this agreement. Andrew **Rowland** co-devised the concept of the project, wrote the first draft of the grant application, organised the arrangements for the visits, undertook direct clinical care in Cambodia, co-delivered the First Aid Training, contributed to the development of the new education and learning resource area, undertook outreach medical visits in Sihanoukville and co-wrote the project report. Joan Livesley co-devised the concept of the project, co-delivered the First Aid Training, undertook and evaluated the consultation workshop with children and young people, designed and created the education and learning resource centre, evaluated the First Aid Training, undertook outreach visits into the community in the Sihanoukville area, co-wrote the project report. Ngov Chanravy co-devised the concept of the project, hosted the UK teams in Cambodia in November 2016 and April 2017, co-delivered the First Aid Training, provided translation of the materials necessary for the evaluation of the children and young people consultation workshop and the First Aid Training and co-delivered and translated the rapid education update seminar. Maggie Eno co-devised the concept of the project, hosted the UK teams in Cambodia in November 2016 and April 2017, provided senior oversight of the two visits from the UK team, organised the necessary permissions for the visits from the UK team, provided pastoral support to the visiting UK team, wrote background information for the project report and participated in the consultation with children and young people. Dim Dora co-devised the concept of the project, hosted the UK teams in Cambodia in November 2016 and April 2017, participated in the rapid educational updates seminar and provided direct

178

clinical care ensuring the sustainability of management plans that were put into place. Den Carter co-devised the concept of the project, coordinated media activity in relation to the November 2016 and April 2017 visits to Cambodia, coordinated social media work in relation to the learning from the project and provided input into the project report.

Supplementary Published Work (10)

Failure to evaluate introduction of female genital mutilation mandatory reporting: The authorship contributor statement is published within the final published work. All authors agreed to the contents of the manuscript, including the contributor statement, prior to publication and publication would not have been possible without this agreement. <u>Andrew Rowland</u> carried out the Freedom of Information Act 2000 request. <u>Andrew Rowland</u> and Felicity Gerry drafted the first draft of the letter. All authors revised the first draft of the letter, contributed to the revised letter and responded to the reviewer's comments.

Supplementary Published Work (11)

Living on a Railway Line: This publication is based on <u>Andrew Rowland</u>'s own independent work and, whilst gratefully acknowledging the support of those individuals set out in Appendix Six of the *Living on a Railway Line* publication (page 303 of *Living on a Railway Line*), <u>Andrew Rowland</u> is the sole author of the work.

Supplementary Published Work (12)

Review of the efficacy of rectal paraldehyde in the management of acute and prolonged tonic-clonic convulsions: The authorship contributor statement is published within the final published work. All authors agreed to the contents of the manuscript, including the contributor statement, prior to publication and publication would not have been possible without this agreement. Richard Appleton, Andrea Gill and Anne Briar Stewart were responsible for the original study idea and design. <u>Andrew Rowland</u> analysed the data.

AUTHORSHIP EVIDENCE

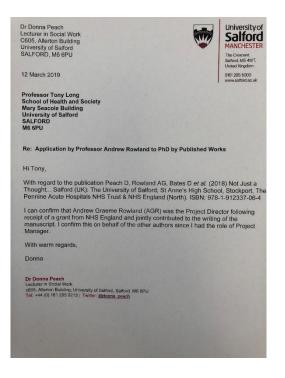


Figure 10: Letter 1 from Dr Donna Peach



Figure 11: Letter 2 from Dr Donna Peach

	Professor Felicity Gerry QC Carmelite Chambers	
	9 Carmelite Street	
	London	
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	18. 020 7350 0000	
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	Dr Yeliz Prior	
	Director of Postgraduate Research Admissions	
	School of Health & Society University of Salford	
	12 March 2019	
	Dear Dr Prior,	
	Re: Application by Professor Andrew Rowland to PhD by Published Works programme	
	Andrew Rowland is Consultant in Paediatric Emergency Medicine at North Manchester	
	General Hospital and Honorary Professor in Paediatrics in the School of Health and Society	
	at the University of Salford. Andrew and I collaborated during our research into Physical	
	Punishment of Children: time to end the defence of reasonable chastisement in the UK,	
	USA and Australia.	
	Our paper, resulting from our research, was published in the international Journal of Children's	
	Rights. Unfortunately, no author contributorship statement was included in the published final	
	version, and I am therefore writing to confirm the following:	
	Andrew Graeme Rowland (AGR) undertook the initial literature review. The chapter,	
	written by AGR in his publication "Living on a Railway Line", was used as the initial	
	first draft of the paper. All authors then jointly contributed to manuscript revisions and	
	further literature inclusion as well as approved the final version of the manuscript for	
	publication.	
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	Professor Fallerry Gerry QC	
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Figure 12: Letter from Professor Felicity Gerry QC

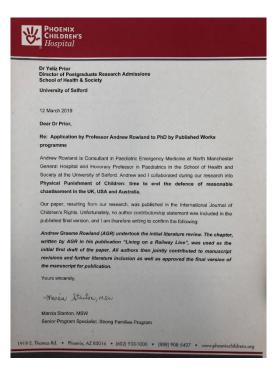


Figure 13: Letter from Marcia Stanton MSW



Figure 14: Letter from Professor Tony Long PhD

APPENDIX TWO

In the paper Defining significant childhood illness and injury in the Emergency Department: a consensus of UK and Ireland expert opinion (5) it was reported that a list of 154 childhood conditions reached positive consensus as significant, 1 condition reached a negative consensus (uncomplicated Henoch-Schönlein purpura), and 37 conditions achieved non-consensus. The consensus was a priori \geq 80% (positive or negative). In this chapter the conditions achieving positive (warranting acute admission to hospital) and negative (not warranting acute admission to hospital) consensus as significant are set out, as well as those conditions achieving non-consensus.

DEFINING SIGNIFICANT CHILDHOOD ILLNESS AND INJURY IN THE EMERGENCY DEPARTMENT: A CONSENSUS OF UK AND IRELAND EXPERT OPINION

Conditions Achieving Positive Consensus

Table 9 displays the illness or injury conditions reaching ≥80% positive consensus for warranting acute admission to hospital. The median Likert scale responses are displayed (1= strongly disagree, 2=disagree, 3=neutral, 4=agree, 5=strongly agree).

Table 9: Illness or injury conditions reaching ≥80% positive consensus for warranting acute admission to hospital

LIST OF CONDITIONS	Median
INFECTION	
Fever in a child under 1 month old	5
Fever in a 1 to 3-month-old appearing unwell or with a WCC <5 or >15 x109/litre	5
Suspected meningitis	5
Suspected sepsis (all causes including neutropenic)	5
Fever in an immunocompromised patient	5
Herpes, chickenpox or shingles infection in immunocompromised patient	5
Ophthalmic eczema herpeticum	4
Suspected encephalitis	5
Orbital (post-septal) cellulitis	5
Suspected mastoiditis	4
Toxic shock syndrome	5
Strongly suspected or confirmed tropical infection involving: malaria, typhoid, or viral haemorrhagic fever (all types)	5
Suspected osteomyelitis	5
Suspected septic arthritis	5
Suspected epiglottitis	5
Suspected bacterial tracheitis	5
Severe pneumonia (oxygen saturations below 92% in air or dullness to percussion or reduced air entry or significant work of breathing or signs of sepsis)	5
Suspected infective endocarditis	5
Scalded skin syndrome	5
An upper respiratory tract infection compromising feeding/oral intake, whereby the child (over 3 months) appears dehydrated and has failed an oral fluid challenge in the department	5
Suspected pyelonephritis in a child who appears unwell with physiological derangement	5
Newly presenting periorbital (pre-septal) cellulitis that has any one of: spread rapidly according to the history, appears extensive/florid	4
2nd presentation of periorbital cellulitis which has not improved after 24 hours or worsened at any time with oral treatment	5
2nd presentation of soft tissue infection that has not improved after 24 hours or worsened at any time since commencing oral antibiotics	4
Suspected pelvic inflammatory disease (with no safeguarding concerns) with signs of systemic illness, signs of tubo-ovarian abscess on ultrasound or clinical signs of pelvic peritonism	5
Acute viral hepatitis with evidence of acute liver failure (encephalopathy or coagulopathy)	5
Non-blanching rash with fever plus any one of the following: signs of appearing unwell; meningism; prolonged CRT; abnormal vital signs; presence of purpura; rash outside SVC distribution; abnormal WCC, clotting or raised CRP	5
Suspected bacterial infection in a systemically unwell child with chickenpox	5

LIST OF CONDITIONS	Median
RESPIRATORY	
Wheeze (viral-induced or asthma) not responding to inhaler or nebuliser therapy or not resolving quick enough in the time allowed within the 4-hour ED wait time to allow safe discharge home	4
Bronchiolitis where respiratory support is needed for either work of breathing or hypoxia, or feeding support is needed, or if there is a RED- FLAG co-morbidity i.e. congenital heart disease, history of prematurity, chronic lung disease, cystic fibrosis, neuromuscular disease, age less than 1 month old	5
Croup where the child still has stridor at rest or respiratory difficulty after administration of oral dexamethasone or inhaled budesonide	4
Any respiratory condition with signs of, or high risk of developing airway compromise	5
Pneumothorax (tension and non-tension)	4
Any respiratory condition requiring supplemental oxygen support (if the child is already on home oxygen, then this definition applies to those requiring escalation of their support)	5
Any respiratory condition requiring non-invasive or invasive ventilatory support (if the child is already on home ventilation, then this definition applies to those requiring escalation of their support)	5
Tension pneumothorax	5
Non-tension pneumothorax (not related to trauma) which is any one of: >2cm on chest x-ray; patient is breathless; patient has an oxygen requirement; post needle aspiration the patient is clinically no better, or the pneumothorax is still >2cm on chest x-ray	5
Pneumothorax (non-tension) secondary to Trauma	5
CARDIAC	
Congestive heart failure (any cause)	4
Suspected or confirmed new diagnosis of cyanotic congenital heart disease	5
Suspected or confirmed duct-dependent lesion	5
Suspected or confirmed total anomalous pulmonary venous drainage	5
Evidence of myocardial ischaemia or infarction	5
New diagnosis of cardiomyopathy	5
Suspected myocarditis	5
Suspected pericarditis	4
Cardiac tamponade (all causes)	5
Suspected Kawasaki disease	5
Acute rheumatic fever	5
Ventricular tachycardia	5
New diagnosis of 2 nd or 3 rd degree heart block, or known heart block which has become symptomatic	5
Collapse with any new findings of: cardiac symptoms in the history (such as exertional dyspnoea), possible obstructive cardiac lesion on examination (such as murmur of aortic stenosis), or abnormal ECG findings suggestive of a cardiomyopathy such as HOCM, or a channelopathy such as Long QT	5
Asystolic (any cause), VF or pulseless VT cardiac arrest, with return of spontaneous circulation after resuscitation	5

LIST OF CONDITIONS	Median
CARDIAC (continued)	
SVT (new presentation or known history) that requires escalation of treatment beyond vagal manoeuvres or adenosine to achieve cardioversion (such as DC-shock or loading with anti-arrhythmic agents). No haemodynamic compromise.	5
SVT (any age, new presentation or previous history) presenting with haemodynamic compromise	5
GASTROENTEROLOGY	
Gastroenteritis with abnormal vital signs/systemically unwell	4
Gastroesophageal reflux: with apnoea or frequent choking	4
Inflammatory bowel disease – new (or suspected new) diagnosis with significant rectal bleeding, suspected acute surgical concerns, or signs of physiological derangement	5
Haematemesis (large volume of blood or sustained bloody vomiting)	5
Gastroenteritis whereby the child (any age) appears dehydrated and has failed an oral rehydration challenge including with an antiemetic	4
Vomiting and/or diarrhoea with any of the following: physiological derangement, large volume of blood or frequent occurrence of blood in stool	5
Abdominal pain with signs indicating a surgical condition or signs of systemic illness including physiological derangement	5
Failure to thrive in an infant who appears unwell	4
NEUROLOGY	
Encephalopathy (all causes)	5
Signs / symptoms of raised intracranial pressure (including idiopathic) not in the context of a head injury	5
Atypical febrile convulsion	4
1 st generalised seizure with any of the following: lasting >5 mins, looking unwell, abnormal development, co-morbidities, head injury, age under 1 year old	4
Status Epilepticus	5
New diagnosis of hydrocephalus	4
New seizures or change in neurology in a child with a VP shunt	5
Suspected blocked, infected or malfunctioning VP shunt	5
Psychosis (organic cause not excluded at this time)	4
Signs/symptoms of focal neurological problem	4
Ongoing reduced or fluctuating level of consciousness	5
Suspected Guillain-Barré or other progressing paralysis syndrome	5
Suspected transverse myelitis	5
Suspected or confirmed cerebrovascular accident	5
Non-traumatic cavernous sinus thrombosis, subarachnoid or intracerebral haemorrhage (suspected or confirmed)	5
Newly presenting Infantile Spasms	4
Status dystonicus	4

LIST OF CONDITIONS	Mediar
TRAUMA	
Signs of traumatic airway injury	5
Head injury with signs of traumatic brain / skull injury on CT scan requiring either acute neurosurgical intervention or a period of neuro-observation	5
Head injury with normal head CT scan but persisting signs of brain injury: reduced / iluctuating GCS, signs of raised ICP, vomiting, abnormal neurology	5
Any traumatic injury / injuries requiring urgent surgical or interventional radiology ntervention or period of observation for greater than the 4-hour ED wait limit allows	5
Trauma associated with signs of cardiovascular compromise / instability	5
Signs of smoke inhalation	5
All circumferential burns	4
Any burn with suspicion of non-accidental injury	5
Any burn that requires immediate in-patient specialist burns team input (as advised by burns team or local burns unit policy)	5
Compartment syndrome	5
Blunt abdominal trauma with on-going pain but normal imaging	4
Head injury, well child, vomited throughout 4 hours in the ED, parents do not want a CT	4
Fractures requiring reduction and period of traction	5
Significant mechanism of injury with no obvious injury identified, but the distress of the child makes completion of the examination difficult	4
SURGERY	
Suspected appendicitis	4
Suspected (if unable to rule out whilst in ED) or confirmed pyloric stenosis	4
Suspected (if unable to rule out whilst in ED) or confirmed intussusception	5
Bowel obstruction (whatever cause)	5
Acute abdomen (any cause)	5
Acute pancreatitis	5
ncarcerated / strangulated hernia (all types)	5
Swallowed foreign body requiring surgical/endoscopic intervention (e.g. button battery)	5
Post-tonsillectomy bleed	5
Suspected testicular torsion	5
Suspected urological tract obstruction	5
Ectopic pregnancy	5
New presentation of conjugated hyperbilirubinemia / obstructive jaundice	4
Suspected necrotising fasciitis	5
Abscess (any) with signs of systemic involvement (such as fever, physiological derangement)	4
ALLERGY	

LIST OF CONDITIONS	Median
DERMATOLOGY	
Steven-Johnson syndrome / erythema multiforme major	5
Erythroderma with systemic derangement	4
Bleeding haemangioma where you cannot achieve adequate haemostasis within the ED	4
ENDOCRINE & METABOLIC	_
Diabetic ketoacidosis	5
Thyrotoxicosis or thyroid storm	5
Adrenal crisis	5
Unexplained hypoglycaemia	4
Symptomatic hypoglycaemia	4
Metabolic acidosis or alkalosis (with no underlying diagnosis assigned at time seen)	4
Decompensation of known metabolic disorder	5
Known metabolic disorder where the child has a concurrent illness and is not tolerating their oral emergency regimen	5
Suspected new metabolic condition	4
Significant electrolyte derangement (for example Na ²⁺ <130, K ⁺ >6)	5
TOXICOLOGY	•
Any poisoning requiring hospital admission for treatment or a period of observation beyond that allowed in the ED, as defined by TOXBASE	5
Medication or recreational drug reaction that results in systemic derangement or physical symptoms e.g. oculogyric crisis	4
MUSCULOSKELETAL / RHEUMATOLOGY	
Inflammatory arthritis (new or known history) with systemic disturbance or unable to control symptoms with simple analgesia/anti-inflammatory drugs	4
HAEMATOLOGY	1
Sickle cell crisis (all forms)	4
Symptomatic thrombocytopenia	4
Evidence of disseminated intravascular coagulation	5
Uncontrolled bleeding (any cause)	5
Anaemia (any cause) that requires a blood transfusion	4
Thrombocytopenia with signs of active bleeding	5
Idiopathic thrombocytopenia purpura (ITP) with signs of active bleeding	4
Altered consciousness or signs of intracranial haemorrhage in a child with ITP	5
RENAL	
Haemolytic uraemic syndrome	5
Acute renal impairment (all causes)	4
Acute on chronic renal impairment	4
Any acute nephropathy with any one of: hypertension, haemodynamic derangement, renal impairment	5
Known history of nephropathy with decompensation of renal function, haemodynamic status	5

LIST OF CONDITIONS	Median
RENAL (continued)	
Symptomatic hypertension	5
SAFEGUARDING	
Bruising, fracture or other injury in a non-mobile child with no medical explanation	4
Any safeguarding scenario where a place of safety for the child cannot be arranged immediately from the ED	5
MENTAL HEALTH	
Deliberate self-poisoning	4
Attempted suicide	5
Severe mood disorder with psychotic features	4
Eating disorders with systemic derangement: electrolyte derangement, significant weight loss, cardiovascular compromise (extreme bradycardia, hypotension), hypothermia, dehydration	5
Self-harm (1st or known previous episodes) where you assess the child/young person is high risk of re-harming themselves if sent home from the ED	5
Suicidal ideation where you assess the child/young person is high risk of carrying out suicide attempt if sent home from the ED	5
MISCELLANEOUS	
New diagnosis (confirmed or suspected) of ANY malignancy or progression/decompensation of a known malignancy	4
Acute life threatening event in an infant (ALTE; newly renamed as Brief Resolved Unexplained Event (BRUE)) with any one of: age < 60 days; born < 32 weeks and corrected gestational age < 45 weeks; more than one presentation with ALTE; duration of event was > 1 minute; CPR required by trained medical provider; concerning historical features; concerning physical examination findings (criteria taken from American Academy of Pediatrics guidance)	5
Pain control - irrespective of cause, need for opiate analgesia (new / escalating / intravenous)	4
Failure of home care package for child with complex medical needs, when parents / carers usually providing high level of medical care at home are unable to do so due to child's worsening illness or parental factors	4
Palliative care not supported in the community	4
Systemically well new-born struggling to establish feeds with >10% weight loss and has an electrolyte abnormality	4

Condition Achieving Negative Consensus

One condition reached ≥80% negative consensus for warranting acute admission to hospital: new presentation of uncomplicated Henoch-Schönlein purpura with a median Likert scale score for admission of 2 (1= strongly disagree, 2=disagree, 3=neutral, 4=agree, 5=strongly agree).

Conditions Achieving Non-Consensus

Table 10 shows the statements (illness or injury) which did not reach consensus (≥80% for warranting acute admission to hospital). The median Likert scale responses are displayed (1= strongly disagree, 2=disagree, 3=neutral, 4=agree, 5=strongly agree).

Table 10: Statements (illness or injury) which did not reach consensus (≥80% for warranting acute admission to hospital)

LIST OF CONDITIONS	Median
INFECTION	
Significant Varicella Zoster (VZV) exposure in immunocompromised patient with known absence of immunity to VZV	4
Newly presenting soft tissue infection that has any one of: spread rapidly according to the history or appears extensive	4
Any soft tissue infection accompanied by signs of systemic illness	4
CARDIAC	1
Collapse in a child who appears well now, but the collapse was associated with any one of: exercise/exertion, sudden onset palpitations, exertional chest pain, auditory stimulus, being in water/swimming, known structural heart disease e.g. aortic stenosis, cardiomyopathy, strong family history of unexplained sudden death in the young or channelopathy such as long QT; where child is now well, clinical examination and ECG appear normal	4
New diagnosis of SVT in a child (non-infant) which cardioverts to sinus rhythm with vagal manoeuvres or adenosine. Child never in haemodynamic compromise	3
SVT in an infant (new presentation or previous history), not haemodynamically compromised	4
GASTROENTERLOGY	
Failure to thrive in an infant who continues to fail to thrive despite an adequate feeding/dietetic plan in place	4
Severe constipation with encopresis and failed home management despite compliance with full escalation of the NICE constipation oral medication pathway	4
NEUROLOGY	
Any generalised seizure lasting > 5mins	3
Generalised seizures occurring at least once weekly in a child not known previously to have epilepsy	3
Increasing seizure frequency in a child with known seizures	3
Atypical seizure pattern in a child with known seizures	3
Uncertainty over seizure duration. Child has made a full recovery	2
Suspected hemiplegic migraine, does not improve with trial of anti-migraine medication	4
Suspected hemiplegic migraine, no specialist neurology input available at time of seeing the patient in the ED	4
TRAUMA	
Simple linear skull fracture with no safeguarding concerns	3
ALLERGY	
Widespread urticarial rash in a child who appears systemically unwell	4
DERMATOLOGY	
Severe widespread eczema not adequately responding to outpatient therapy where compliance with treatment regime is good	4
Unexplained petechial rash, in a well child with normal CRP, WCC and clotting results and no safeguarding concerns	2
ENDOCRINE & METABOLIC	
New diagnosis of Type 1 Diabetes (not in DKA)	4

LIST OF CONDITIONS	Median
MUSCULOSKELETAL / RHEUMATOLOGY	
Limp with suspected sinister underlying pathology	4
Slipped upper femoral epiphyses	4
Non-linear or depressed skull fracture. Child is well. CT brain not showing evidence of a neurosurgical emergency. No safeguarding concerns	4
HAEMATOLOGY	1
Any newly presenting coagulopathy	4
RENAL	
New diagnosis of nephrotic syndrome	4
New diagnosis of glomerulonephritis	4
New diagnosis of nephritic syndrome	4
Blood pressure >95 th centile, child otherwise well	3
SAFEGUARDING	•
Suspected fabricated illness, not judged to be at immediate risk of harm, without any current pre-planned admission date and time	3
MISCELLANEOUS	1
Parental factors: parents say they are not coping with the child's acute illness at home and there is not adequate home support in available from friends and family	4
Parental factors: despite clinician reassurance with adequate explanation about their child not needing hospital admission, parents strongly wish that their child is admitted for observation and assessment	4
New finding of pregnancy in a child under 16 years. No safeguarding concerns	2
Problem with a tracheostomy which cannot be solved in the ED or by the parents. No immediate airway threat	4
Problem with an implanted device (for example gastrostomy or suprapubic catheter) needing specialist input, for example replacement which cannot be achieved in the ED	4
Frequent attendance for medically unexplained symptoms, such as blackouts, pseudo-seizures, pain, off legs, dizziness	3
Crying baby that will not settle, but you cannot find anything medically wrong with them in the urgent care setting	4
Systemically well new-born struggling to establish feeds with >12% weight loss (electrolytes normal)	4

APPENDIX THREE

THE PUBLISHED WORKS

Core Published Works

Full references for the seven core published works underpinning this thesis are set out in **Table 11**. These published works are all available from the University of Salford Institutional Repository (USIR)⁷.

Label	Title	Reference
(1)	Physical punishment of children: time to end the defence of reasonable chastisement in the UK, USA and Australia	Rowland AG , Gerry F & Stanton M. Physical punishment of children: time to end the defence of reasonable chastisement in the UK, USA and Australia. The International Journal of Children's Rights 2017; 25(1): 165-195
(2)	Mandatory Reporting of Female Genital Mutilation in Children in the UK	Malik Y, <u>Rowland AG</u> , Gerry F, <i>et al.</i> Mandatory Reporting of Female Genital Mutilation in Children in the UK. <i>British Journal of Midwifery 2018</i> ; 26(6): 377-386
(3)	Not Just a Thought	Peach D, <u>Rowland AG</u> , Bates D <i>et al.</i> (2018) Not Just a Thought Salford (UK): The University of Salford, St Anne's High School, Stockport, The Pennine Acute Hospitals NHS Trust & NHS England (North) ISBN: 978-1-912337-06-4

Table 11: Core published works underpinning this thesis

⁷ <u>http://usir.salford.ac.uk.salford.idm.oclc.org/view/authors/58020.html</u>

Table 11: (continued)

Label	Title	Reference
(4)	Outcomes from the Children and Young People's Advocacy House Consultation Event – MediaCityUK	Livesley J, <u>Rowland AG</u> , Fenton K, <i>et al.</i> (2018) Outcomes from the Children and Young People's Advocacy House Consultation Event – MediaCityUK. The University of Salford. ISBN: 978-1-912337-02-6
(5)	Defining significant childhood illness and injury in the Emergency Department – a consensus of UK and Ireland expert opinion	Lillitos P, Lyttle M, Roland D, Powell C, <u>Rowland AG</u> , Chapman S, Maconochie I. Defining significant childhood illness and injury in the Emergency Department – a consensus of UK and Ireland expert opinion. <i>Emergency</i> <i>Medicine Journal 2018;35 685-691</i> (Impact factor: 2.046)
(6)	Diagnostic accuracy of PAT-POPS and ManChEWS for admissions of children from the emergency department	Cotterill S, <u>Rowland AG</u> , Kelly J, <i>et al.</i> Diagnostic accuracy of PAT-POPS and ManChEWS for admissions of children from the emergency department. <i>Emergency Medicine</i> <i>Journal</i> 2016;33:756-762 (Impact factor: 2.046)
(7)	Refining and testing the diagnostic accuracy of an assessment tool (PAT-POPS) to predict admission and discharge of children and young people who attend an emergency department: protocol for an observational study	Riaz S, <u>Rowland AG</u> , Woby S, Long T, Livesley J, Cotterill S, Heal C, Roland D. Refining and testing the diagnostic accuracy of an assessment tool (PAT-POPS) to predict admission and discharge of children and young people who attend an emergency department: protocol for an observational study. <i>BMC Paediatrics</i> 2018; 18:303 (Impact factor: 2.042)

Supplementary Published Works

Full references for the five supplementary published works supporting this thesis are set out in **Table 12**. These published works are all available from USIR⁸.

Label	Title	Reference
(8)	Life on the tracks	Rowland AG (2019). Life on the tracks. The University of Salford (UK) ISBN: 978-1-912337-32-3
(9)	From sick kids to SicKids!	Rowland AG , Livesley J, Ngov C <i>et al.</i> (2017). From sick kids to SicKids! SicKids and the University of Salford (UK) ISBN: 978-1-912337-03-3
(10)	Failure to evaluate introduction of female genital mutilation mandatory reporting	Gerry F, <u>Rowland AG</u> , Fowles S, <i>et al.</i> Failure to evaluate introduction of female genital mutilation mandatory reporting. Archives of Disease in Childhood 2016; 101 : 778-779 (Impact factor: 3.258)
(11)	Living on a Railway Line: Turning the tide of child abuse and exploitation in the UK and overseas: international lessons and evidence-based recommendations	Rowland AG. Living on a Railway Line: Turning the tide of child abuse and exploitation in the UK and overseas: international lessons and evidence-based recommendations. The Winston Churchill Memorial Trust & University of Salford; October 2014

 Table 12: Supplementary published works supporting this thesis

⁸ <u>http://usir.salford.ac.uk.salford.idm.oclc.org/view/authors/58020.html</u>

Table 12: (continued)

(12)	Review of the efficacy of rectal paraldehyde in the management of acute and prolonged tonic- clonic convulsions	Rowland AG , Gill AM, Stewart AB, <i>et al.</i> Review of the efficacy of rectal paraldehyde in the management of acute and prolonged tonic-clonic convulsions . Archives of Disease in Childhood Sep 2009; 94(0):720-723 (Impact factor: 3.258)
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