Participating In CaMKIN:

Impact On Patients

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Cristina is a Lecturer in Digital Health. With a background in digital business, Cristina worked in the industry before joining Academia. Her research is promoting collaborative work and co-creation with the local communities to make deeply impactful positive change. Passionate about co-designing digital products that meet the needs of users, Cristina co- founded KIN to allow patients to share and access information and support. Cristina’s research expertise extends to digital methods, engagement and digitization of learning for which she received numerous awards.

Lisa Garwood-Cross, University of Salford

Lisa’s research at the University of Salford focuses on the intersections between social media and digital health, and her work specialises in the use of digital methods and analysis of large-scale social media datasets. Lisa has worked on projects with Kidney Care UK, the Greater Manchester Health and Social Care Partnership, and UKRI relating to the use of social media and digital technologies in health. She also researches the use of YouTube and social media influencers for Sex and Relationship Education.

Rob Finnigan, Kidney Information Network

Rob Finnigan is an ADPKD patient who is now into his eighteenth-year post-transplant under the care of Salford Royal's renal team. He is the north-west Patient Advocate for Kidney Care UK. Elsewhere, he manages the Kidney Information Network (KIN) under the direction of Dr Cristina Vasilica & Professor Paula Ormandy.

Tara Bashford, Kidney Information Network

In her 6 years as a renal patient Tara has gained an enormous insight into the life of someone living with a long-term health condition, which she brings to the Kidney Information Network. "Being able to utilise my experience and support the network has been invaluable, it’s an incredible resource for patients".

Patti O’Kane, Liverpool University Hospitals

Having worked closely with a family managing the devastating effects of ill health during a year as an Au Pair aged 18, Patti was inspired to return to the UK and qualify as a nurse. Patti is passionate about ensuring that patients have a voice in all aspects of their care and has seen the benefits that peer support can bring to patients with chronic illness such as CKD. “Prior to CaMKIN the CKD patient support group had ceased to exist. Now CaMKIN has more than 300 members who are actively supporting each other. Through the moderator patients have been able to raise concerns and it has provided feedback that helps ensure we deliver a service to patients based on their need.

Prof Paula Ormandy, University of Salford

Paula is a Professor in Long Term Conditions, her research expertise includes integrated care, self-management, patient education and information provision using digital and social media. Paula is a co-founder of KIN, and founder and co-chair of the Kidney Patient Involvement Network (KPIN) to foster high quality patient involvement, strengthen the kidney patient voice and increase patient leaders. Paula is a Q Fellow with the Health Foundation and a champion for improving patient experience and quality of care for people managing multiple long-term conditions.

Contents

Executive Lay Summary 5
  The current report shows the following findings: 5
Introduction 6
  The impact of Chronic Kidney Disease (CKD) 6
  Chronic kidney disease and information need 7
  Social media and patient peer support 7
  Social media for patient-centred changes in service 7
  CaMKIN and The Kidney Information Network 8
  Aims of this report 9
Methods 10
  Sample 10
  Facebook Data collection and preparation 10
  Data analysis 10
    Creation of themes and subthemes 11
    Directed analysis of data 12
    Familiarisation and making sense of data 13
  Survey 14
Findings 15
  Facebook comment analysis 15
  Improved understanding and awareness regarding health 15
    Sharing useful health information 16
    Utilising the group to gather health information or perspectives from lived experience 17
    Self-organised Q&A sessions with medical professionals 17
  Improved self-management of health and wellbeing 17
    Creation of in-group support network 17
    Group motivation for self-managing diet and fitness 18
    Encouragement to self-manage health 18
  Improved health and wellbeing outcomes 18
    Support-network for company and anxieties during shielding 19
    Using group to express difficulties and frustrations in life 19
    Improved health outcomes through group support 19

Changed attitudes leading towards new capacity and awareness 20
  Seeking/sharing information about in person services in relation to COVID-19 20
  Discussion around returning to Nursery/school settings 20
  Clarifying information that may otherwise have been clarified with healthcare professionals 21
  Questions about safety and shielding 21
Patterns of usage in the CaMKIN Facebook group 21
Survey results 22
  Impact Statements 23
Discussion 26
Conclusion 29
Recommendations 29
Further research 30
Acknowledgements 30
References 31

Matrices

Matrix 1 The Framework developed for data analysis 12
Matrix 2 Data search terms 12
Matrix 3 Impact Framework of themes and sub-themes 13

Figures

Figure 1 Data analysis process 11
Figure 2 Flow of health information into the CaMKIN Facebook Group 16
Figure 3 Facebook group activity by time of day 21
Figure 4 Group activity in relation to traditional working hours 22
Figure 5 Age groups 22
Figure 6 Access to health care information 23
Figure 7 Informed about the condition 23
Figure 8 Access to peer support 23
Figure 9 Mental health management 24
Figure 10 Social isolation during COVID-19 24
Figure 11 Support during COVID-19 24
Figure 12 Potential for information flow in CaMKIN 27

Executive Lay Summary

This report describes the impact of the Cheshire and Merseyside Kidney Information Network (CaMKIN) on kidney patients, families, and carers, who are members of the network. It presents the analysis of data generated by members through participation in the group (6,385 posts and comments) and a complementary survey (61 CaMKIN users).

Cheshire and Merseyside Kidney Information Network (CaMKIN) is a localised online network, established in 2019, part of the Kidney Information Network (KIN). CaMKIN/KIN consists of a website (https://kinet.site/), Facebook micro-communities (CaMKIN and GMKIN), Twitter, YouTube and Instagram account.

The current report shows the following findings:

- CaMKIN/KIN has been widely accessed. The website has noted 32,829 visitors (3,197 returning visitors), who visited 87,560 pages. CaMKIN Facebook membership consists of 328 members; GMKIN of 461 members, and both, continue to grow. On Twitter, KIN has 1470 followers and on Instagram 133 followers. KIN YouTube channel has 39 subscribers and hosts a series of KIN videos (7,500 views).
- Members used the group to seek and share information about chronic kidney disease, improving understanding and awareness of their chronic illness.
- The CaMKIN groups provided a form of localised support network with both in person and online opportunities for support.
- The CaMKIN group self-organised question and answer sessions with health professionals to reduce the impact on health services and provide information to clinically vulnerable shielding patients, who may be reluctant to visit their health professionals.
- During the COVID-19 pandemic, CaMKIN members reported access to the group contributed to positive mental health outcomes for clinically vulnerable patients who were shielding. Some CaMKIN users utilised the group as a place to ask questions and develop awareness of the fluctuating situation during the COVID-19 pandemic.
- The moderator role remained vital in stimulating conversations, curating information, and maintaining links between CaMKIN and service providers.
- The localised nature of the CaMKIN group helped to develop and sustain a safe and trustworthy community.
- The Group has been well supported by the wider renal team at Royal Liverpool Hospital which has promoted the Group to all its patients.
- CaMKIN can be used to develop insights into service provision and to feed into positive changes to local health services.

Overall, the analysis demonstrates that this patient-centred community provides 24-hour online peer-support and access to health information, which can improve health and wellbeing. It highlights an untapped opportunity to utilise CAMKIN to further develop service provision and communication between hospitals and patients. Further research is required to roll out and evaluate embedding KIN into local service provision and developing a patient network at a regional and national level.

Introduction

Worldwide, the number of people with long term conditions is increasing. These long-term conditions require careful management, by both patients and service providers. The use of social media has begun to be explored within health care for patients to exchange information and lived experiences with each other or increase access to health professionals. Social media can provide access to out-of-hours information and peer support, potentially leading to satisfaction of information needs, improved self-management and patient outcomes, at reduced costs to health service providers.

Cheshire and Merseyside Kidney Information Network (CaMKIN) is a localised online network, which uses a range of social media platforms to provide peer support to patients with chronic kidney disease (CKD). CaMKIN is part of the Kidney Information Network (KIN), founded and shaped as a patient-centred intervention, which also includes the original KIN group in Greater Manchester (GMKIN). GMKIN was found to meet information needs, health-related and social outcomes on a small scale.

This report begins by contextualising the impact of chronic kidney disease before reviewing literature on information need in chronic health conditions, peer support via social media and the opportunities social media interventions may provide to feed into a change in services. The report then outlines the context in which CaMKIN and the Kidney Information Network were established and developed. The aims, methods and findings will then be discussed, along with recommendations for the future development of CaMKIN within the wider KIN network.

The impact of Chronic Kidney Disease (CKD)

Managing long-term health conditions is a global challenge which has necessitated innovative patient centred care, including patient use of electronic health systems (World Health Organization, 2011; Department of Health, 2013; World Health Organization, 2007; NHS England, 2014; National information Board, 2014; Borgermans, Marchal, Busetto, et al, 2017; Van de Belt, Engelen, Berben & Schoonhoven, 2010; Glasgow, Nelson, Kearney, et al, 2007). Chronic kidney disease [CKD] is a long-term health condition, with approximately 3 million CKD patients in the UK and 40-45,000 premature deaths caused by CKD annually. Although there is no cure for CKD, there are treatment options to help patients live with their chronic illness, such as transplant and dialysis, however these still leave patients with reduced kidney function. The cost of kidney disease in the UK is high: each year there are approximately 100,000 deaths from Acute Kidney Injury, a sudden drop in kidney function, with costs to the NHS between £434 million and £620 million annually; almost 30,000 people in the UK are on dialysis each year; approximately one third of renal patients experience depression and no UK renal units provide the recommended number of specialist renal social workers to support kidney patients through the process (Kidney Care UK, 2020). Within this context, prevention, self-management and support are therefore essential to help CKD patients navigate their life changing chronic condition.

Chronic kidney disease and information need

Effective provision of information is a determinant in aiding patients in the self-management of their conditions (Astin, Closs, McLenachan, Hunter & Priestley, 2008). Patients with chronic kidney disease may not recognize their information needs (Ormandy, 2011) or find the information they require to reduce the uncertainty of the condition is not available (Burns,2015). However, increasing patient knowledge through information provision has been shown to: improve functional adjustment, reduce stress and facilitate coping (Timmins, 2006; Ankem, 2006); improve well-being and personal control (Hepworth & Harrison, 2004); create more knowledgeable and competent patients (Lambert & Loiselle, 2007); increase self-management and self-efficacy (Harrison, et al, 1999; Lorig, et al, 2001) which then has the potential to improve health behaviour, and quality of life (Coulter & Ellins, 2007; Davies, 2010); and reduce dependency on health services (Hepworth & Harrison, 2004).

Patients access health information from a number of sources, however one study found that almost 75% of patients begin looking for health care information via search engines and nearly 33% have used social media by the time their search is complete (Thackery, et al, 2013). Social Media applications can allow patients access to information related to their health, aiding them in making informed choices, enhancing patient empowerment (Van De Belt, et al, 2010) and allowing them to contribute their own ‘user generated content’ for others (Kaplan & Haenlein, 2010; Kata, 2012).

Social media and patient peer support

Chronic illness can be a lonely experience, and patients with long term conditions value learning about the lived experience of other individuals with a similar health condition (Vasilica, 2015) and accessing peer support (Ormandy, 2011; Burns, 2015). Utilising social media for healthcare enables patients with similar health conditions to connect and create peer-support networks (Dhar et al, 2018; Attai et al, 2015; Ormandy, 2008) with health communication between patients enabling them to manage their illness and share their own experiences (Kata, 2012). Patients may engage with social media to achieve specific health and social goals (Vasilica, 2015) such as social engagement with others who understand their condition (Dhar et al, 2018) or seeking to meet their health information needs through understanding the experiences of others (Vasilica, 2015). Social media can be used to exchange information and trigger positive outcomes in long-term conditions (Merolli, Grey & Martin-Sanchez, 2013). Systematic reviews of online peer-to-peer communities suggest that they offer a supportive space for daily self-care related to chronic illness and a valued place to strengthen social ties and exchange knowledge and experience that extends beyond the illness and medical care (Kingod, Cleal, Wahlberg & Husted, 2017; Allen, Vassilev, Kennedy & Rogers, 2016).

Social media for patient-centred changes in service

Social media may provide benefits beyond information need and the development of peer support, with opportunities for changes that reduce impact on health services. A systematic review into the impact of information technology on patient engagement and behaviour change found that 88.8% of studies showed positive impact on patient behaviour, 82.9% reported increased patient engagement and 81% of the social media studies had positive impact on both health outcomes and patient engagement (Sawesi et al, 2016). Further systematic reviews have found that patients use of social media for healthcare can lead to more equal communication and harmonious relationships between patient and healthcare professional (Smailhodzic, Hooijsma, Boonstra, et al, 2016). In addition to these impacts social media has been looked at to increase productivity and reduce costs for modern healthcare (Bugshan, Hajli, Lin, Featherman & Cohen, 2014). However, there may be further opportunities to identify potential social media integration with healthcare services, not only to provide productivity and cost savings, but also to potentially feed back into the patient-centred development and improvement of healthcare services.

CaMKIN and The Kidney Information Network

The Cheshire and Merseyside Kidney Information Network (CaMKIN) was established in 2019 as part of the Kidney Information Network (KIN), providing CKD patients 24-hour online access to information and support regarding their condition. The Kidney Information Network (KIN) began with Greater Manchester Kidney Information Network (GMKIN). Established in 2013, the GMKIN hub was theory informed and co-designed in consultation with CKD patients, carers and health professionals and incorporated social media platforms with active users, including Facebook, blogging, and a forum (Vasilica, Brettle & Ormandy, 2020).

The Facebook group was initially public to attract new membership and then closed (with content visible only to group members) to protect the confidentiality of the information posted. GMKIN was moderated by a manager and a patient who screened blogs and posts for potential health risks and referred to health professionals as appropriate. Members were actively encouraged to take an active role in the community growth to foster underlying bonds. Relationship building and community commitment were facilitated using the principles of social capital (bonding, bridging, and linking in Vasilica & Ormandy, 2017; Putnam, 2000), which involved creating an identity based on shared values, interests, and goals, local interest (North West) and humour. Evaluation of GMKIN found that patient-generated information shared via social media contributed to satisfaction of information need and triggered positive social and health-related outcomes, including a positive impact on patient's self-efficacy and self-management, which can be seen as a means toward achieving measurable health outcomes such as improved kidney function. Patients also reported psychological benefits such as increased confidence and positivity, alongside social benefits including confidence to seek employment. Patients also found information to aid with self-management of their condition such as tips on diet and discovered unmet information needs around their CKD, such as treatment options (Vasilica, Brettle & Ormandy, 2020).

Given the initial positive outcomes from GMKIN, in 2019 the Kidney Information Network (KIN) was created and expanded to the Cheshire and Merseyside region with the launch of CaMKIN.

The creation of CaMKIN to cover these areas supported local health development plans such as Liverpool's 'Digital Liverpool' strategy to improve the health and wellbeing of citizens through digital innovation. A new bespoke website system was designed to facilitate site specific sections to local KINs. Currently, KIN consists of a website (https://kinet.site/), Facebook micro-communities (CaMKIN and GMKIN), Twitter, YouTube and Instagram account. The website has been accessed by 32,829 visitors, amongst which 3,197 are returning visitors, who visited 87,560 pages. CaMKIN Facebook membership consists (June 2021) of 328 members; GMKIN consists of 461 members, and both, continue to grow. On Twitter, KIN is followed by 1470 members and 133 followers on Instagram. Meanwhile the KIN YouTube channel has 39 subscribers and hosts a series of KIN videos, amongst which the CaMKIN promotional video. Across all videos the account has received 7,500 views.

Patients can be signposted to CaMKIN through their local healthcare team or by other patients and join the group for localised CKD peer support. The group organise meet up sessions both in person and online and since its inception the group has grown to include 303 members.

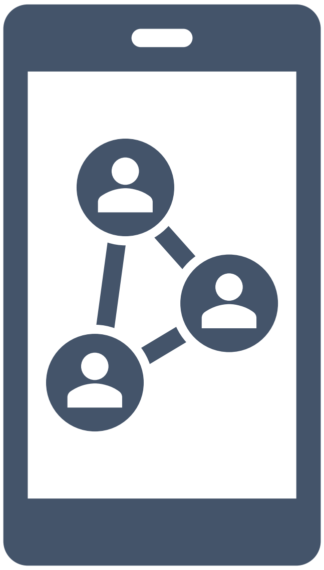
Aims of this report

This report details findings from content analysis of the Facebook data generated during the project to determine the impact of CaMKIN on patient health awareness, self-management and wellbeing outcomes. The analysis is supplemented by an online survey completed by CaMKIN users in December 2020.

The objectives for this report are to provide evidence of the impact of CaMKIN on

- Improved understanding and awareness about health.
- Improved self-management of health and well-being.
- Improved health and well-being outcomes.
- Changed attitudes leading towards new capacity and awareness.

Methods



This study employs a digital methods approach to analyse social media data and gain insights into contemporary social life (Rogers, 2013).

> ***This is achieved through a framework and content analysis of CaMKIN Facebook dataset.***

The Facebook dataset was analysed to determine a matrix of themes and subthemes related to the impact of CaMKIN. It began with an initial matrix of key themes, which was iteratively updated in a structured and unstructured way (allowing for the identification of new sub-themes) to systematically make sense of key determinants of impact (Elo & Kyngäs, 2008).

> ***The result of the analysis is complemented with additional evidence from a questionnaire provided to CaMKIN Facebook members***.

Ethical approval for the study was obtained from the University of Salford Ethics Committee. Given the sensitive nature of the personal health sharing conducted in the group, group members anonymity was protected throughout the study. No personal data from participants was reported, and analysis excluded any identifiable information. To ensure this anonymity is retained, given the nature of the live and continuing CaMKIN Facebook micro-community, no full direct quotations were used in this report to avoid inadvertently identifying group members.

Sample

The sample comprised 303 CKD patients registered in the CAMKIN Facebook group on 31 December 2020. 61 CaMKIN members completed the questionnaire.

Facebook Data collection and preparation

Data was collected from the CaMKIN Facebook group using data scraping, a process which downloads a copy of all posts and comments within a time frame set by the researchers. The data was scraped using Grytics software (Facebook Groups Analytics & Management Tool). The anonymous dataset consisted of 1,119 posts and 5,266 responses, downloaded on 31 December 2020. The extensive qualitative data source was analysed using a bespoke digital tool - Big Content Machine (BCM) - developed at Salford University.

Data analysis

Using a similar approach to Vasilica, et al. (2021), this study used a stepped approach that combined framework with content analysis. The process involved data collection and preparation, development of initial framework (matrix 1), directed analysis to update and create a final framework (matrix 3) familiarisation and sense making throughout the process (Figure 1).

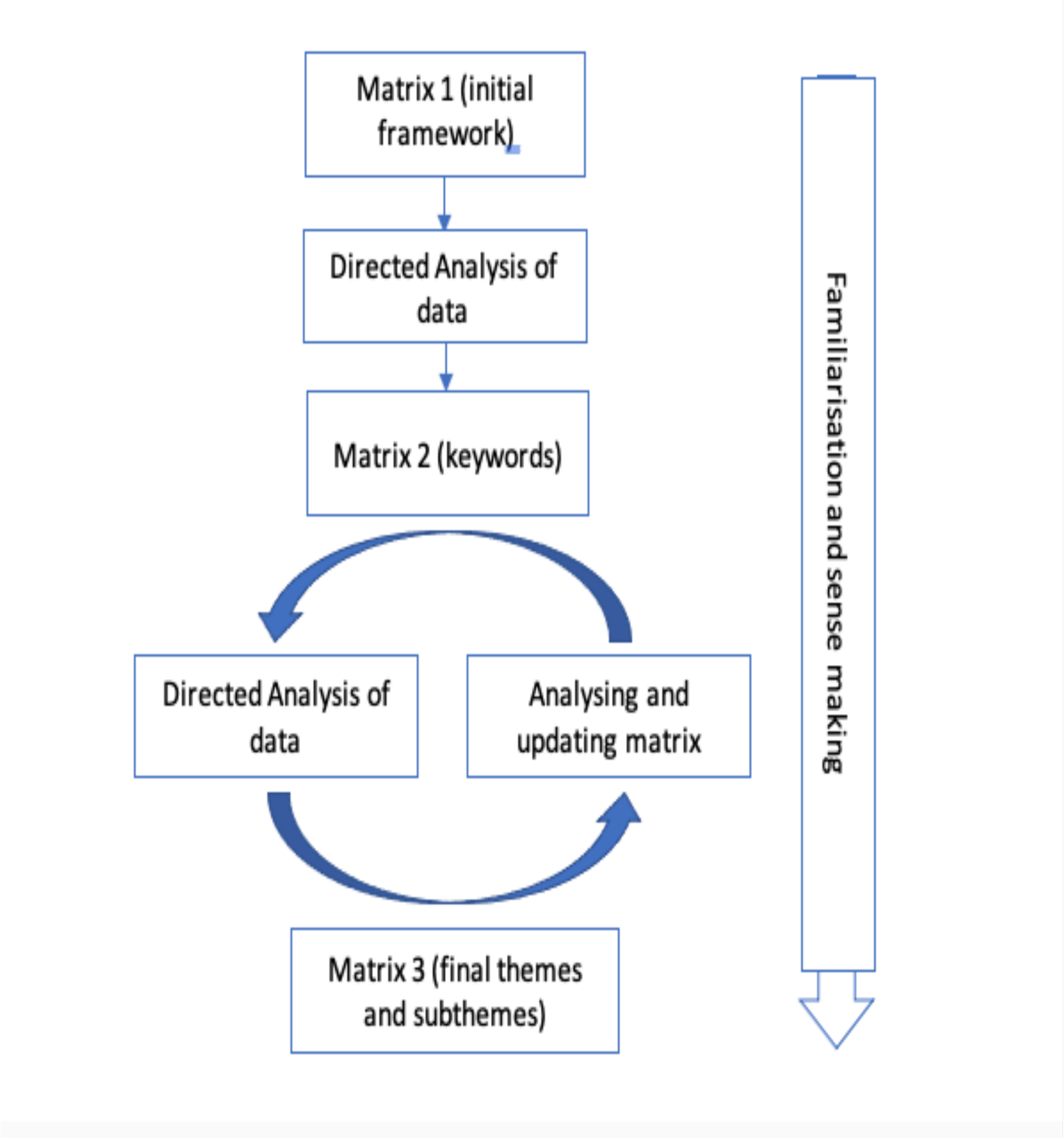


Figure 1 Data analysis process

Creation of themes and subthemes

The researchers created the initial framework to conduct a focused exploration of the impact of CaMKIN on the CKD patients and their families who used it. The framework was developed by the project team using evidence from previous research on the impact of social media (Patel et al., 2015; Vasilica, 2015; Kingod, 2017; Vasilica, Brettle, Ormandy, 2020) and topics important to kidney patients (Ormandy, 2008). The framework

(Matrix 1) consisted of four key themes and was used to conduct framework analysis on the data to discover if and how the data contributed to potential areas of impact.

Matrix 1 The Framework developed for data analysis

Understanding and awareness about health
Self-management of health and well-being
Health and well-being outcomes (eg reduced anxiety, social isolation, confidence, social outcomes)
Changed attitudes leading towards new capacity and awareness

Directed analysis of data

The database was interrogated with a directed analysis using the themes outlined in Matrix 1. The posts and comments were reviewed to determine additional search terms, which were added to the framework (Matrix 2).

Matrix 2 Data search terms

Root word	**Alternative 1**	**Alternative 2**	**Alternative 3**
Help	Helped	Helpful	Helping
Grateful			
Advice	Advise		
Know	Didn't know	Don't know	
Aware	unaware		
Support			
Useful			
Frustrating	Frustrated		
Outcome	This group		
Health	Mental health	stressed	stress
Manage	Managing		
Improved			
Question	Questions	Information	experience
Covid	Covid-19	Coronavirus	
Do I need	Should I	Can I	

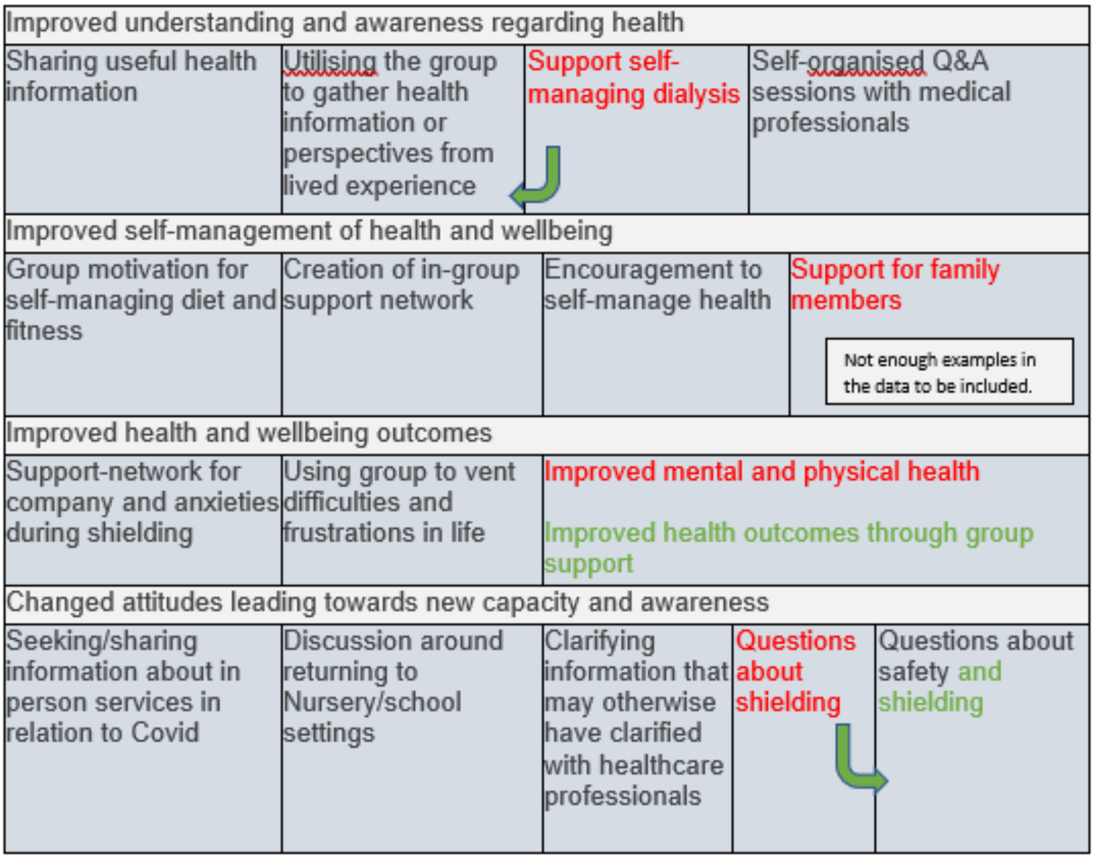
The iterative directed analysis process continued in an inductive way to refine the matrix. These repetitive steps continued until no other themes emerged and the final matrix was defined. In total from the 4 themes 13 sub-themes were identified (Matrix 3).

Matrix 3 Impact Framework of themes and sub-themes

Improved understanding and awareness regarding health			
Sharing useful health information	Utilising the group to gather health information or perspectives from lived experience	Self-organised Q&A sessions with medical professionals	
Improved self-management of health and wellbeing			
Group motivation for self-managing diet and fitness	Creation of in-group support network	Encouragement to self-manage health	
Improved health and wellbeing outcomes			
Support-network for company and anxieties during shielding	Using group to express difficulties and frustrations in life	Improved health outcomes through group support	
Changed attitudes leading towards new capacity and awareness			
Seeking/sharing information about in person services in relation to COVID-19	Discussion around returning to Nursery/school settings	Clarifying information that may otherwise have clarified with healthcare professionals	Questions about safety and shielding

Familiarisation and making sense of data

Thousands of posts and comments were read during the directed analysis process and a selection of relevant posts and comments were collated into the framework spreadsheet to test and develop the sub-themes. For each sub-theme a minimum of 8 posts or comments were collated although where there was a large variety of data on the sub-theme more examples from the data were included. Having accumulated examples from the data, the sub-themes were re-worked, removed or combined based on observations in the data. For example, an initial sub-theme ‘support self-managing home dialysis’ was merged into ‘using the group to gather health information or perspectives from lived experience’ as reviewing the data identified that these posts were often questions to gather perspectives from other CKD patients experience. A visual example of how the sub-themes were developed whilst making sense of the data is provided in Flowchart 1 below.



Improved understanding and awareness regarding health

- Sharing useful health information
- Utilising the group to gather health information or perspectives from lived experience
- Support self-managing dialysis
- Self-organised Q&A sessions with medical professionals

Improved self-management of health and wellbeing

- Group motivation for self-managing diet and fitness
- Creation of in-group support network
- Encouragement to self-manage health
- Support for family members

Not enough examples in the data to be included.

Improved health and wellbeing outcomes

- Support-network for company and anxieties during shielding
- Using group to vent difficulties and frustrations in life
- Improved mental and physical health
- Improved health outcomes through group support

Changed attitudes leading towards new capacity and awareness

- Seeking/sharing information about in person services in relation to Covid
- Discussion around returning to Nursery/school settings
- Clarifying information that may otherwise have clarified with healthcare professionals
- Questions about shielding
- Questions about safety and shielding

🟥 = Removed from a previous iteration of the matrix 🟩 = Added or merged in matrix 3

Flowchart 1 Example of subthemes development

Survey

A questionnaire to capture information on CKDu patients' perceptions of the value and impact of CaMKIN was distribted via the CaMKIN Facebook group by the moderators in December 2020. Reminders were posted by the moderators to encourage maximum responses.

The questionnaire was built and distributed using Bristol Online Survey (BOS) Software. Descriptive statistics using the present functions in BOS were used to report the

Findings

The themes seeking to clarify the impact of CaMKIN on patients managing CKD include:

- ***Improved understanding and awareness regarding health***
- ***Improved self-management of health and wellbeing***
- ***Improved health and wellbeing outcomes***
- ***Changed attitudes leading towards new capacity and awareness***

The themes and adjacent subthemes will be explored in detail the next section; starting with the Facebook dataset analysis, complemented by the results of the survey.

Facebook comment analysis

The dataset scraped from the CaMKIN Facebook group covered a period from 7th June 2019 to 31st December 2020 and was made up of 1,119 posts made by users to the group, and 5,266 comments made in response to posts. The data set (6,385 posts and comments) provided a range of information about the needs, daily life and struggles of CKD patients. Patients regularly used the CaMKIN Facebook group to access support, information and to discuss the management of their condition. However, the data also provides an insight into the isolation and shielding experiences of immunosuppressed and clinically vulnerably patients during the COVID-19 pandemic and the role of peer-support in sustaining mental health through these unprecedented circumstances. The findings of the comment analysis will be presented through the lens of the framework analysis and the themes and subthemes identified within the data (see Matrix 3).

Improved understanding and awareness regarding health

Throughout the data there were numerous instances of patients using the CaMKIN Facebook group to improve understanding of their condition and share information and awareness related to CKD. These were sorted into three significant sub-themes:

- Sharing useful health information
- Utilising the group to gather health information or perspectives from lived experience
- Self-organised Q&A sessions with medical professionals

These sub-themes each relate to a different way in which health information is exchanged and flows into the Facebook group for improved understanding and awareness of health. As can be seen in Figure 2 below.

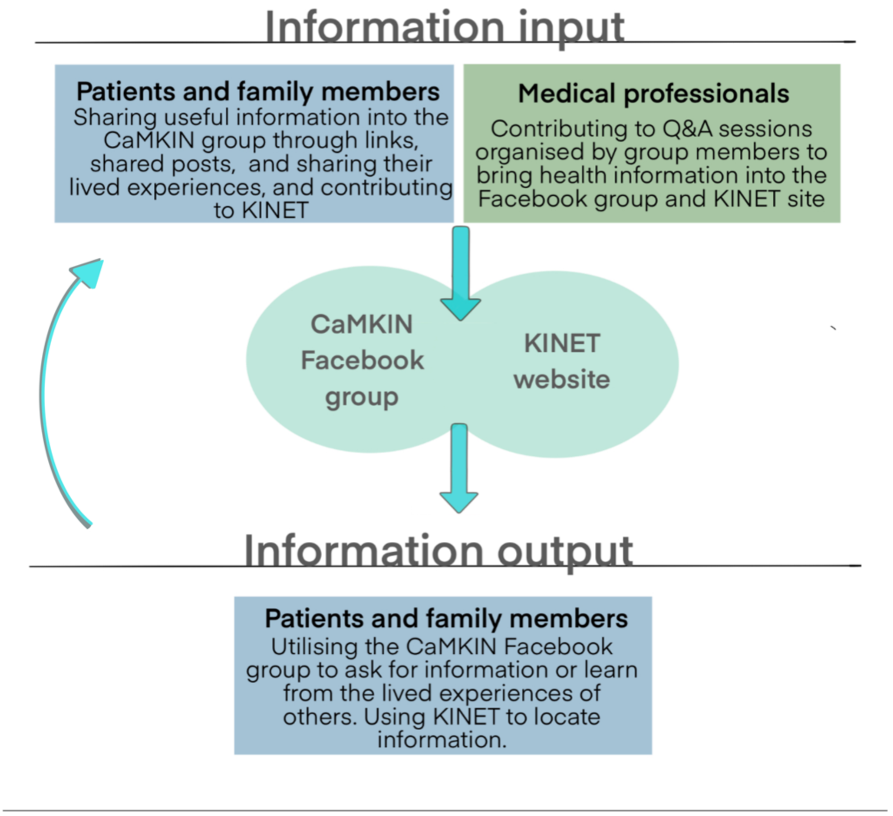


Figure 2 Flow of health information into the CaMKIN Facebook Group

Although patients and family members utilising the CaMKIN group to ask for information is an information output, it also forms part of a circular information cycle, whereby the seeking of information contributed to further information provided in the group that others who may not feel comfortable posting can view. Further development of figure 1 and the information flow of KIN will be covered in detail in the discussion section of this report. The following sections will demonstrate the findings from this flow of information in further detail.

Sharing useful health information

The CaMKIN group facilitated regular peer to peer sharing of health information from several sources, including emerging research study results, local hospital, useful resources, apps, websites, patient blogs and personal experiences. Information shared came from reputable sources such as Kidney Care UK, National Kidney Foundation, homedialysis.org and messages from local consultants. Information from these sources was shared on a number of topics including fluid restriction, understanding how dialysis works, the H2Overload app by the National Kidney Foundation and information about the change to opt-out organ donation. Other personal sources were shared; one group member shared multiple blog posts written about their husband's journey to home dialysis, meanwhile others shared posts they had written for the KINET blog. In addition, some patients shared advice that they had received, which could be useful to others in the group, for example one user shared during a period of hot weather that they had been alerted that dialysate/saline for home dialysis patients needed to be disposed of if stored over certain temperatures, and recommended that patients speak to their renal teams about the matter.

Into 2020 updates on the COVID-19 virus, effects for CKD patients and shielding advice were shared by group members to improve awareness. For example, given the uncertainty by some group members about the suitability of the COVID-19 vaccines in development for immuno-suppressed individuals following transplant, information was shared to reassure group members that the vaccine did not contain the live virus.

Utilising the group to gather health information or perspectives from lived experience

Patients regularly used the group to seek opinions or lived experience from other CKD patients to improve their understanding of their condition. For example, one patient asked if a local renal psychologist existed in the area to help them manage the mental health impacts of their condition, meanwhile another asked for information about if it was possible to work full-time whilst on dialysis. Patients appeared to value the lived experience of other patients in helping them develop their understanding of procedures and treatments they were considering. Or, one group member asked if anyone in the group had a button hole fistula as they were considering a change from their existing fistula due to problems, another sought tips for how to tape down needles for nocturnal dialysis, and one patient asked if anyone had needed an angioplasty because of a stenosis as they were experiencing anxiety around it. At times, group members responded to some user shared health information stating that they were ***'really really useful'*** or ***'very helpful'***.

Self-organised Q&A sessions with medical professionals

The CaMKIN Facebook group also self-organised question and answer (Q&A) sessions with medical professionals to answer group members questions on a number of topics, including shielding advice during COVID-19, post-transplant recovery and dietary advice. These Q&A sessions also led to changed attitudes leading towards new capacity and awareness, which is discussed later in this report. Patients were able to submit questions prior to the sessions on the Facebook group. The question-and-answer format enabled patients to ask questions they might not want to bother their renal teams about, for example in a Q&A on shielding from COVID-19, one patient asked if it was safe to have a takeaway, another asked if they could hug their friends and family if they knew they were COVID-free, and one enquired if shielding individuals would be given vaccine priority. Several users thanked the organisers and provided positive feedback that they ***'found the information very helpful'*.**

Improved self-management of health and wellbeing

CaMKIN had an impact on supporting the self-management of users' health and wellbeing in a number of ways. Most significantly, CaMKIN provided a form of peer support network offering both in person and online opportunities for support. This support then created additional opportunities to encourage self-management of health, with additional sub-themes of 'group motivation for self-managing diet and fitness' and 'encouragement to self-manage health' being identified within the data.

Creation of in-group support network

Members of CaMKIN reassured each other about upcoming procedures, sent well wishes, checked in on one another and bonded through shared experience. One group member walked through the steps of a procedure and what to expect for an anxious patient, reassuring them ***'you'll be fine'***. Other patients mentioned feeling much more emotional support compared to their early experiences of their renal journeys. Another CaMKIN user shared that the kind wishes they received on the news of their transplant had really helped them. Later they specified that a message from a prominent poster in the group had aided them in getting their ***'head on straight'*** the night they got the call for the transplant, helping them remain ***'calm and focused'***. Some group members stood out in the data as influencers within the group, with this specific prominent poster becoming a central figure in group support, organising activities and developing the sense of community within the group.

Several commenters on the group identified a positive atmosphere within the CaMKIN community, as they felt it contrasted the negativity in other, larger, kidney patient groups on Facebook. With the narrative around the group emphasising that it was ***'wonderful'*** to meet people going through the '***same experiences***', or expressing those conversations in the group made them realise they were '***not alone***'.

Group motivation for self-managing diet and fitness

The analysed data indicates additional improvements in the self-management of patients CKD, particularly in providing a motivation for the self-management of diet and fitness. Managing weight to be put on the transplant list and oversee kidney health can be a challenge for individuals. Group members created their own '**healthy choices**' weight loss accountability group, using a supportive 'weight watchers' style, and discussed the use of the diet and weight loss tracking app 'My Fitness Pal' to follow each other's journeys towards weigh loss.

Users also shared milestones in weight loss or exercise and motivated each other towards weight loss goals for transplant health. One group member shared updates as they went through the Couch to 5k running programme, another shared their success in reducing their BMI to get on the transplant list and expressed that they would happily assist others on the same journey. Group members responded to these posts with congratulatory and supportive messages, creating an atmosphere of encouragement. One group member mentioned that the formation of the healthy choices group for diet and exercise could be a ***'lifeline'*** in aiding people qualify for transplant.

Encouragement to self-manage health

Additionally, group members encouraged each other to take proactive steps in self-managing their health by recommending when it might be prudent to reach out to their renal team, access local psychological services or ring services such as the '111' emergency health information line, urging them ***'don't wait'***. One user encouraged a commenter to take on the advice they had received about making healthy eating choices, using their own personal experience of wishing they had done the same to stay off dialysis a little longer. In another example from the data a commenter suggested that a patient and their spouse may find it beneficial to speak to a renal psychologist to help them work through the difficult time they were having with experiences relating to CKD, while a different group member encouraged someone struggling with their mental health to reach out to a renal psychologist as they ***'definitely recommend it'.***

Improved health and wellbeing outcomes

Although it can be difficult to identify the real-time or long-term health benefits of belonging to a group such as CaMKIN, there were some areas where potential for improved health and wellbeing were observed in the data. Alongside the potential health outcomes from increased understanding and self-management of condition, CaMKIN positively contributed to mental health of group members in several ways. The peer-support provided patients an outlet to air frustrations about the CKD journey, quell anxieties, and support each other's mental health. One area where this outcome became essential was the onset of COVID-19 as many clinically vulnerable people were required to shield in their homes to protect their health.

Support-network for company and anxieties during shielding

The inability for clinically vulnerable patients to leave home safely posed risks to the mental health of CKD patients who may already be suffering with poor mental health due to their condition. However, the CaMKIN group took on an active role in encouraging positive mental health outcomes. The group facilitated zoom meet up sessions, including a session on Christmas day to provide company to anyone who would be alone or wanted company. One group member referred to the CaMKIN group as an '***invaluable source of support***' during the COVID-19 pandemic, while another added into one of their comments:

> '***Thank you for being there for me and with me during some of the scariest months 2020 had to offer***'.

The group also provided opportunities for patients to have their questions about shielding and safely de-shielding (venturing back outside the home) answered by professionals to decrease anxiety around this process. Several patients expressed concern, asking if it was actually clinically safe for them to leave shielding, or if it had only been recommended as it was necessary for the economy, and used the Q&A and group discussion to discuss these concerns.

Using group to express difficulties and frustrations in life

The CaMKIN group provided a space for patients to express frustrations about their life and condition. One group member shared their challenges of navigating the benefits system as a CKD patient, another expressed frustration about how chronic fatigue was affecting their quality of life. Patients shared about many different parts of their experience, including the response from others. One patient discussed that they had '***had enough***' of people telling them that they looked '***really healthy'*** when they were experiencing a series of co-morbidities that some days left them unable to move. Finally, one other topic that was discussed by multiple users was vexation at having to advocate for themselves against consultants, GPs and other healthcare workers who they felt did not believe or understand them in certain situations surrounding their condition or symptoms. For example, one patient expressed that they had trouble convincing a new GP that their pain was from gout because the GP believed women could not get gout, until their test results came back to the contrary.

Improved health outcomes through group support

The interlink between CKD and mental health came up in the data at multiple points, In some cases patients directly linked the group to positive mental health outcomes;

> ***'This group has really saved my mental health since having my transplant [...] I only wish I had known about it before'***

In other examples, there were signs that increased communication and encouragement around mental health may lead to improved health outcomes. For example, one group member expressed that they had been experiencing anxiety and asked in the group if the hospital had support for mental health.

Another patient praised a commenter who posted about starting renal counselling and encouraged them by sharing their own mental health journey in realising that they were not 'broken'. One patient expressed that they had been struggling mentally for some time but had not been offered access to a renal psychologist, to which other group members responded with information about which local hospitals had the service available. Finally group members used the community to gain help with managing health related anxieties, for example one person asked what others do to calm their ***'pre-op nerves'***.

Changed attitudes leading towards new capacity and awareness

CaMKIN provided patients in the Cheshire and Merseyside area with a place outside of their traditional healthcare settings to share and receive health information related to CKD. In 2020, as the COVID-19 pandemic caused challenges for health services and access issues for some clinically vulnerable patients, the group became an opportunity to share information about the capacity of the local health services in Cheshire and Merseyside. Patients used CaMKIN to discuss or clarify information they may otherwise have sought from their individual healthcare teams, potentially reducing demand on the local services through the self-organisation that occurred within the group. The group also facilitated discussions around awareness of safety for CKD patients related to school or nursery settings, and shielding.

Seeking/sharing information about in person services in relation to COVID-19

As the COVID-19 pandemic created strain on NHS services, CaMKIN offered CKD patients a place to ask questions and develop awareness of the changing situation. Patients exhibited an awareness that their local services may be overwhelmed, busy or not suitable at certain times if they were shielding and thus used the CaMKIN group to identify which services were running, for example, just as the first national lockdown was about to be enforced, one patient asked if anyone had been for bloods at a local hospital to help them understand if they would be able to go for their own appointment the following day, meanwhile another patient asked if it was safe to go to a local facility for bloodwork and if they should alert the team that they were shielding.

> ***Patients also reassured each other about the safety of visiting in-person services, with one patient posting after their hospital visit for bloodwork that they were 'in and out in 10 minutes' and that the hospital was 'as safe as it can be', and another sharing a drop-in service renal patients could use.***

Finally, the group was utilised as a place to encourage and share opportunities to book phone consultations. For example, a renal dietician from a Merseyside hospital messaged within the group to let patients know that although their presence would not be as visible on the ward due to COVID-19, that they would be providing a virtual service via telephone consultations.

Discussion around returning to Nursery/school settings

Several discussions around awareness of safety related to childcare were noted in the data in relation to COVID-19. These varied from parents unsure about sending their children back to school whilst they were still shielding, to teachers and nursery staff who sought opinions on their safety to return to work. A parent enquired if others in the micro-community were struggling to decide if they should send their children back to school and expressed that they were personally ***'going round in circles'*** trying to make a decision. One group member asked if they were putting themselves in danger by returning to work as a nursery nurse as they were due to return to work the following week, mentioning that they felt ***'lost and confused'*** on the topic. Another mentioned being unwilling to send their child back to school as the teachers had not been provided PPE, and a teacher asked a question about what would be considered '*Covid-safe working conditions*' due to them being a post-transplant and pregnant.

> ***These patients utilised CaMKIN to improve their awareness of safety and capacity issues in these public working environments which may impact their health.***

Clarifying information that may otherwise have been clarified with healthcare professionals

CaMKIN also offered patients a place to ask questions they might have otherwise asked health professionals, potentially reducing demand on health services. This was achieved through organised question and answer sessions with medical professionals facilitated online. During a Q&A session related to transplants, patients asked a number of questions including what to do if they see a small amount of blood in their urine several weeks after transplant, how much and how soon exercise could be undertaken post-transplant, and how to safely diet post-transplant without causing a negative knock-on effect to blood results.

Beyond the Q&A sessions users still utilised the group to ask questions that might otherwise have involved them phoning or visiting their local services, for example, patients asked which unit they should call now that they had been discharged from a specific service, if they should organise delivery for their anti-rejection medication, and if anyone knew what changes were being made to a local hospital's shared-care system.

Questions about safety and shielding

As discussed earlier in this report, through the group's organised Q&A sessions with a medical professional, patients were able to increase their awareness of safety around COVID-19 and ask questions they had about shielding without needing to add additional strain to their local health services. Some patients asked when it was safe to return to work, others asked questions about when transplants would be allowed to recommence, while some wanted to know if there would be any changes across the board to renal patient's medication to reduce risks of infection.

Patterns of usage in the CaMKIN Facebook group

In addition to analysing the comment content of the CaMKIN Facebook community, the data was analysed to identify patterns of usage. The analysis found that the group had been used at every hour of the day or night at some point during the data collection period, with the least popular time for usage being 4am (n=12 post and comments) and the most popular time being 9am (n=474 posts and comments).

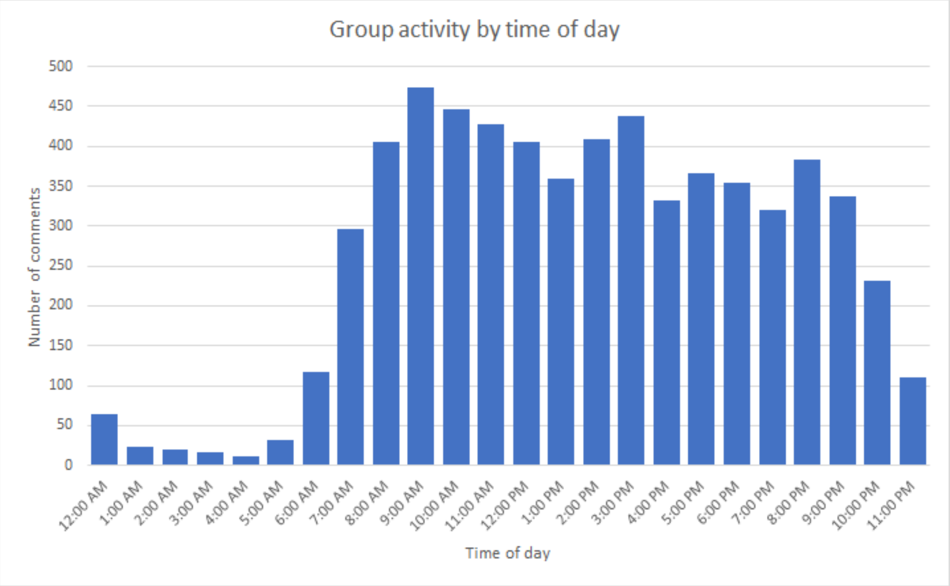


Figure 3 Facebook group activity by time of day

The majority of posts and comments in the CaMKIN Facebook community were made between 7am and 10pm (Figure 3). Given the breadth of this usage, the time data was analysed to see how active the group was both during traditional working hours where patients can have access to their GP (Figure 4).

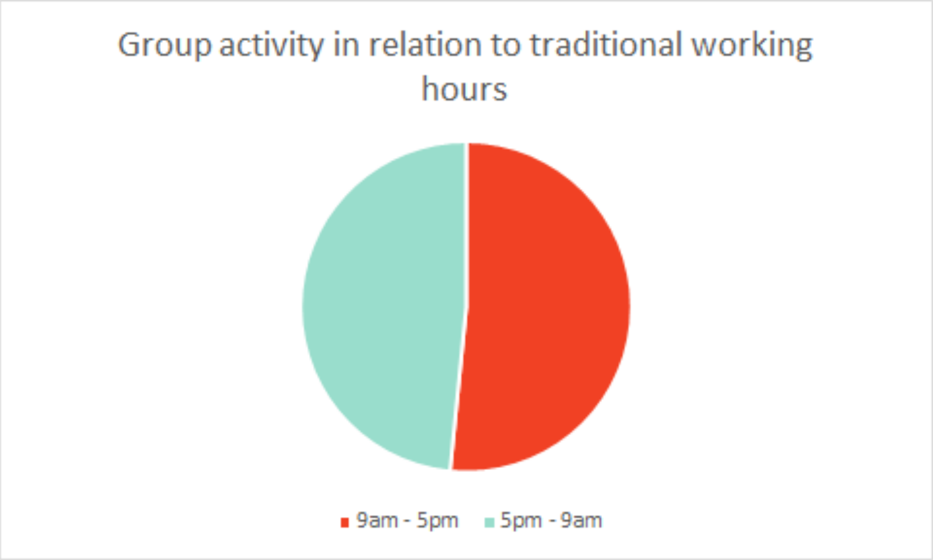


Figure 4 Group activity in relation to traditional working hours

51.57% (n=3293) of the CaMKIN activity was made during regular GP hours of 9am – 5pm, with 48.43% (n=3092) of posts and comments being made outside of this period. This demonstrates that the group receives considerable patient engagement outside of conventional practice hours, where CaMKIN can provide peer-to-peer support.

Survey results

A total of 61 CaMKIN users completed the questionnaire between 8-31 December 2020 (93.4% patients and 6.6% carers). They ranged in age between 18 to over 70; with 16.4% of the sample between 18- 40 years , 80.3% age between 41-70 years old, and 3.3% age over 70 (Figure 5).

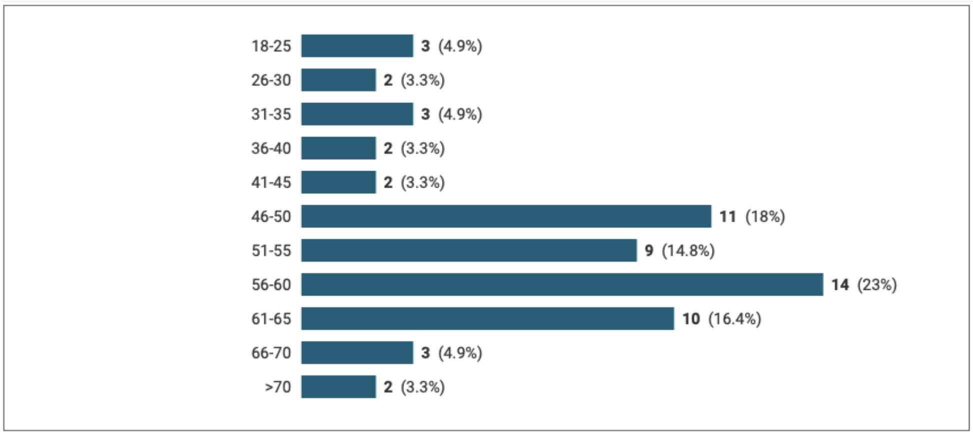


Figure 5 Age groups

Impact Statements

The results of the survey are presented in detail under each statement below. The statements explored members access to health care information, feeling more informed about their condition, access to peer support, mental health management, impact on social isolation and the support they received during the COVID-19 pandemic.

- *CaMKIN has improved my access to health care information*

More than half of participants agreed or strongly agreed that CaMKIN improved access to health care information (Figure 6).

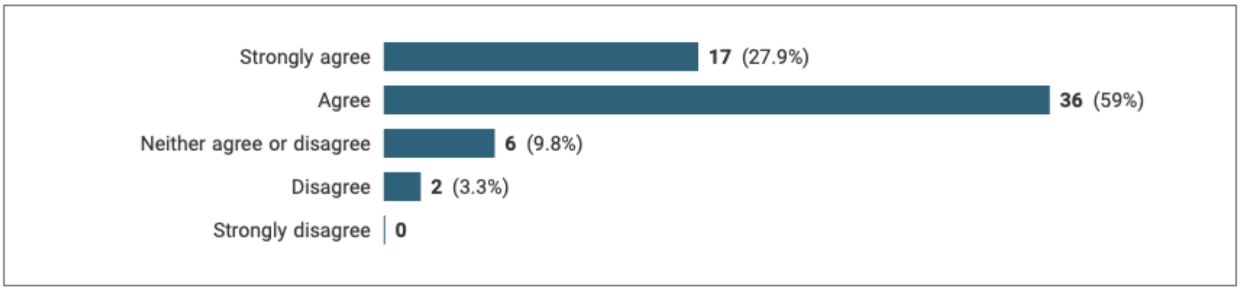


Figure 6 Access to health care information

- *CaMKIN has made me feel more informed about my condition*

The majority of sample indicated that the information generated through CaMKIN and KIN allowed them to be more informed about the condition (Figure 7).

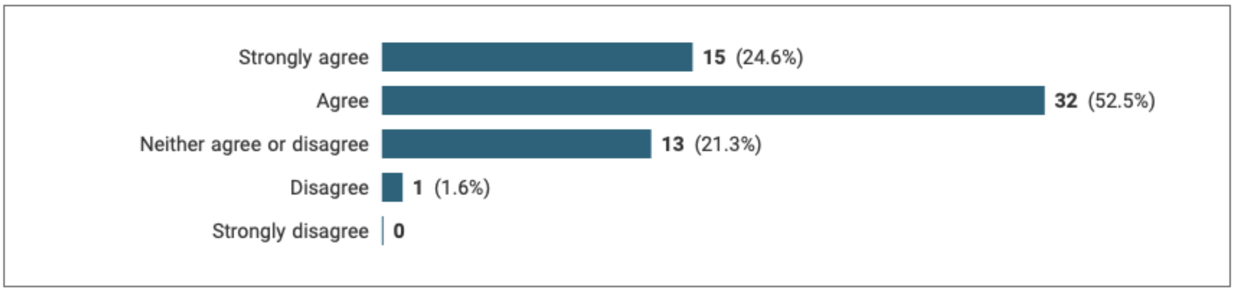


Figure 7 Informed about the condition

- *CaMKIN has provided me with valuable peer support*

All participants valued the peer support received through CaMKIN, with 75.4% of respondents strongly agreeing and agreeing with the statement (Figure 8).

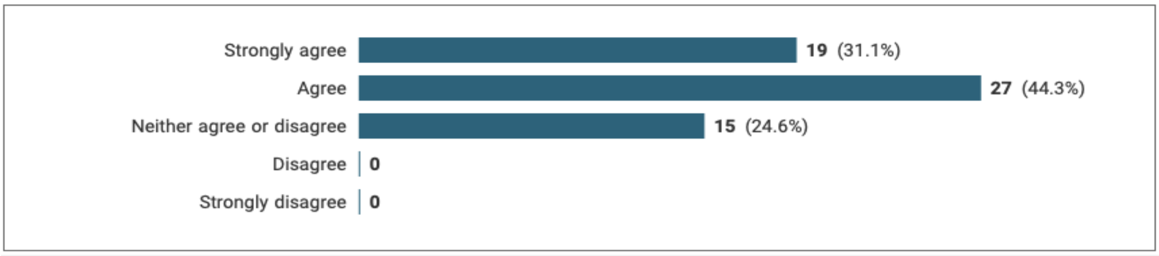


Figure 8 Access to peer support

- *CaMKIN has helped me manage my mental health*

Almost half of respondents (48.8%) stated that CaMKIN helped them with the management of mental health. 52.5% neither agreed or disagreed with the statement. A small percentage (4.9%) disagreed (Figure 9). The statement was introduced as a question after the analysis of Facebook data indicated that the group had a positive impact on mental health management.

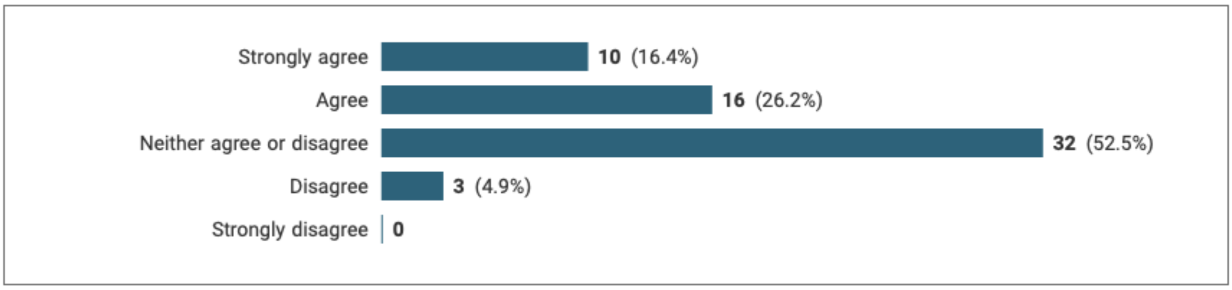


Figure 9 Mental health management

- CaMKIN has helped me feel less alone and socially isolated

Almost half of the respondents indicated that CaMKIN contributed to reduced social isolation, whilst 31.1% neither agreed or disagreed. Only 1.6% of respondents disagreed that CaMKIN reduced social isolation. (Figure 10).

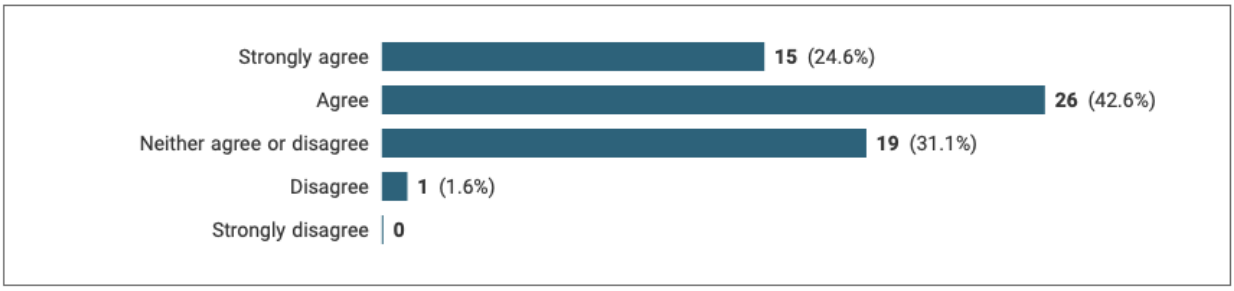


Figure 10 Social isolation during COVID-19

- CaMKIN has provided valuable support during the COVID-19 pandemic

More than half of CaMKIN members, who completed the survey, acknowledged that CaMKIN provided valuable support during the COVID-19 pandemic (70.6%), whist 16.4 were not sure (Figure 11).

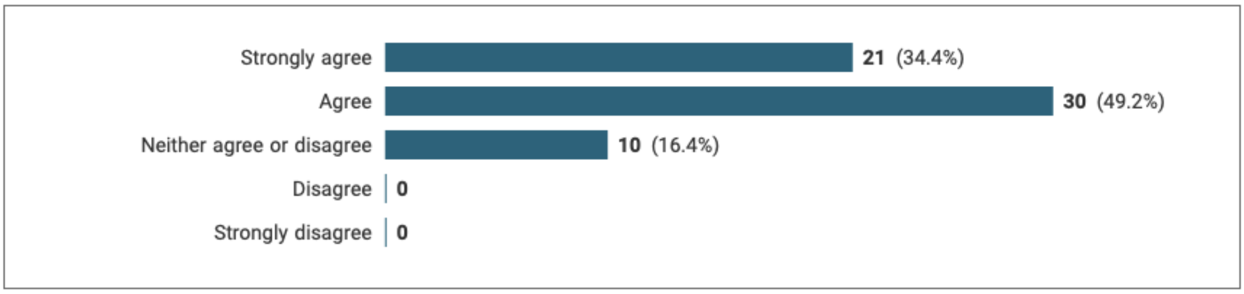


Figure 11 Support during COVID-19

Overall, the findings of the survey reinforced the themes that emerged from the analysis of the CaMKIN Facebook group dataset.

Results highlight that the vast majority of respondents benefited from access to health care information (86.9 %), which made them feel more informed about their condition (77.1%). Patients received valuable support from peers (75.4%). Almost half of the sample agreed or strongly agreed that CaMKIN contributed towards management of mental health and more than half stated that it reduced social isolation. In addition, during the COVID-19 pandemic, CaMKIN has provided valuable support.

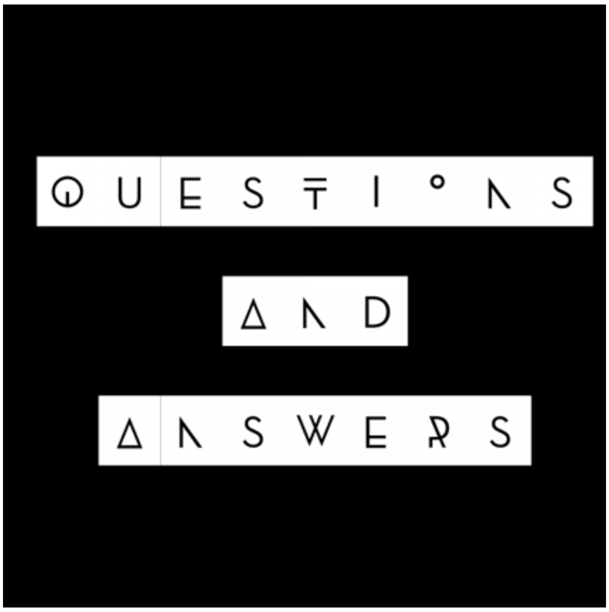
Discussion

The data from CaMKIN demonstrates that this patient-centred community provides peer-support for the management of CKD where patients can seek and share relevant health information. The data also suggests improved health and wellbeing can be obtained through the peer-support available in the group, findings aligned with previous research on GMKIN (Vasilica, 2015; Vasilica, Brettle and Ormandy, 2020).

This was particularly exemplified through the way the group was used by clinically vulnerable patients for support whilst shielding during the COVID-19 pandemic. Usage data also identifies patients are frequently using CaMKIN outside of traditional GP practice hours, and the comment analysis also observed patients self-organising peer-support in periods where some services are usually inaccessible, such as Christmas day. An interesting finding that emerged, initially from analysis of the Facebook dataset, and then validated in the survey, was that CaMKIN contributed to management of mental health. Although not set out to provide mental health support, the findings from CaMKIN further strengthen evidence that online micro-communities can have a positive influence on mental health (Vasilica, Brettle & Ormandy, 2020).

Further research is necessary to investigate the potential of social media micro-communities to improve mental health outcomes for patients with CKD/Long Term Conditions.

However, the data suggests there may be ways to utilise CaMKIN and the Kidney Information Network for greater impact. One finding of interest is the way the CaMKIN group members self-organised to meet their own health information needs. The moderator organised question and answer sessions with local healthcare providers on several topics. Members of the CaMKIN group were asked to provide their questions prior to each Q&A session and these were taken to health professionals who answered the questions. These answers were then shared on the Facebook group and hosted on the KINET website. Currently this has been explored on a small scale by group members, however, it indicates there may be ways to integrate the use of KIN to reduce demands on local health services, improve communication between patients and healthcare providers, and feed back into service provision through the identification of unmet patient needs.



At present, analysis of CaMKIN and KIN have been focused on patient benefits, but this new data suggests that there is merit in the further development of KINs use. Earlier in this report, the flow of information in the network was presented (Figure 2). However, alongside being a valuable resource for patient information and peer-support, this structure could be used to develop insights into service provision and to feed into positive changes to local health services, as demonstrated below in Figure 12.

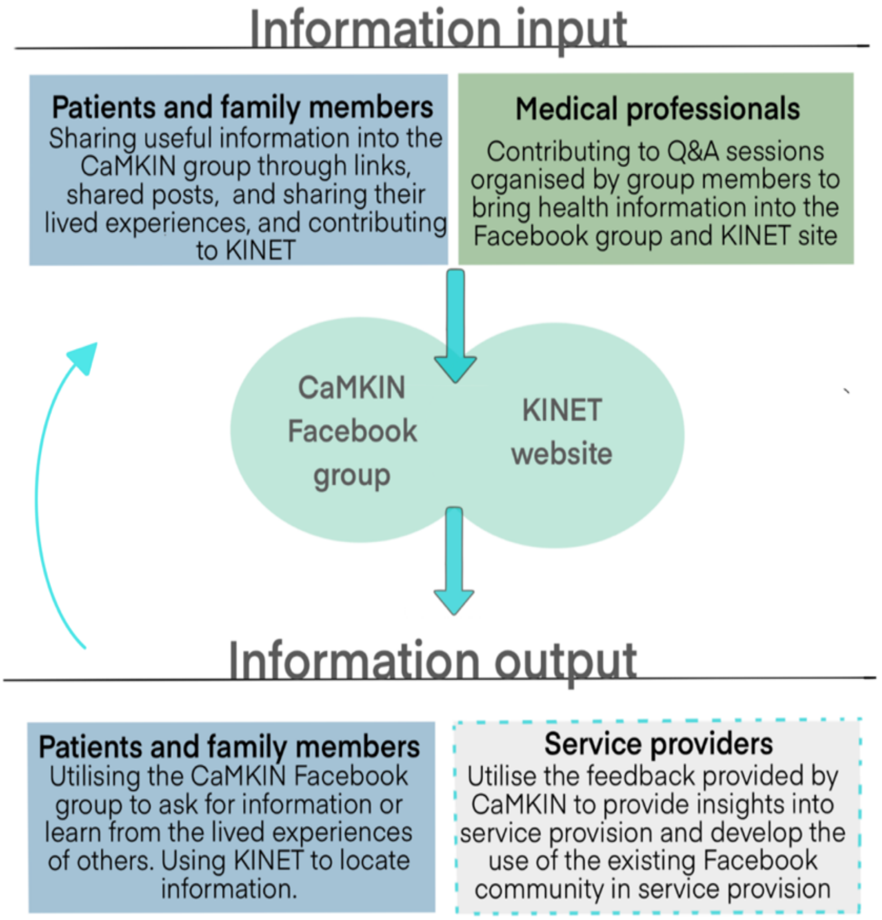


Figure 12 Potential for information flow in CaMKIN

At present the opportunity to include health information from medical professionals via question-and-answer sessions or other means (e.g. sharing information) follows a more informal route within the CaMKIN Facebook micro-community, and up until now the potential to utilise CaMKIN to strengthen service provision has not been fully integrated within the hospital pathways.

Therefore, further research is needed to test this hypothesis and establish a protocol for integrating CaMKIN and other local KIN hubs into local service provision and development. Utilising the flow of information in CaMKIN to feed back into service provision may be possible through increasing Q&A sessions; utilising the Facebook community to provide live digital training on relevant CKD topics such as home dialysis or managing nutrition; and providing live information about updates to services, new initiatives and capacity at local facilities. Additionally, creating a more formal route to receive and act on ’intelligence’ generated through the group to improve service provision.

The role of a patient moderator role to increase the self-organising capabilities of CaMKIN and to provide avenues of reciprocal communication between patients and service providers for service improvements has been invaluable. Moderation remain a key element of successful online health communities (Huh, McDonald, Hartzler & Pratt, 2013; Vasilica, 2015), as moderators play a critical role in developing vibrant online health communities by stimulating discussions (Huh, Marmor & Jiang, 2016), converting lurkers into active participants (Resnick, Janney, Buic & Richardson, 2010), and ensuring that online communities are safe spaces (Matzat & Rooks, 2014) where participation net-ettiquette is reinforced and accurate information is shared (Huh, McDonald, Hartzler & Pratt, 2013). Some online communities combat potential misinformation by employing health professionals in moderator roles (Huh, Marmor & Jiang, 2016) meanwhile other peer support health communities limit user's ability to ask for health advice through moderation practices, however this has been found to stunt the flow of communication between peers (Huh, 2015). However, as CaMKIN benefits from working in a small, localised community, the patient moderator acts as a bridge between hospitals and CaMKIN patients, whilst retaining the patient-centred autonomy of the community. Given the usage data identified in this report, it may be preferential for the moderator to have flexible working hours to account for the group activity which takes place outside of regular working hours.

Conclusion

CaMKIN is a patient led community where CKD patients and their families can share experiences with those in a similar situation and receive support from both, peers and professionals, as appropriate.

The data analysis of the Facebook group dataset and the survey suggest that this innovative micro-community helps CKD patients understand their condition better and improve health awareness through information sharing and peer support.

A novel aspect of CaMKN included professionally developed information (e.g. Q&A).

This leads to improved self-management, stimulated through peer support for maintaining healthy lifestyles, looking after well-being and continuous encouragement. Demonstrated through a self-reported mechanism and dataset analysis, peer support contributed to improvements in mental health and reduction of social isolation. During the COVID-19 pandemic, CaMKIN offered CKD patients a place to ask questions and develop awareness of the changing situation to enable them better manage health and safety.

The moderator of the group had a significant input on the group's behavioural intentions, support and information shared. It contributed towards a positive atmosphere and novel ways to stimulate engagement and information provision.

The data provides insight into an untapped opportunity to utilise CaMKIN to develop service provision and communication between hospitals and patients. Further research is recommended to establish a protocol for integrating CaMKIN and other local KIN hubs into local service provision and development, with the addition of a paid patient moderator possibly providing increased capacity for this expansion.

Recommendations

- CAMKIN/KIN remained a reliable source of support and information during the pandemic. Further efforts are required to incorporate CaMKIN within service flow as a continuous source of information and communication with members.
- Discover other influential community members and build capacity through training and continuous support.
- Increase KIN resources (blogs and Q&A) to maximise the impact of the network (sharing the information with patients who opt not to join Facebook but access information via KIN).
- Increase reach and the membership through advertising CaMKIN with staff and patients.
- Provide culturally appropriate information to increase uptake amongst those from ethic groups.

Further research

Further research is required to roll out and evaluate embedding KIN into local service provision, and developing a patient network at a regional and national level. It will develop understanding of using social media localised micro-communities (CaMKIN / KIN) for influencing service provision (e.g communication with patients, receiving intelligence on how to better shape services to meet the needs of service users).

The finding that CaMKIN contributed to better mental health also requires further investigation to understand in more depth the context, mechanisms and outcomes for mental health support through CaMKIN.

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References

Allen, C., Vassilev, I., Kennedy, A., Rogers, A. (2016). ‘Long-Term Condition Self-Management Support in Online Communities: A Meta-Synthesis of Qualitative Papers’. J Med Internet Res. 18(3):e61

Ankem, K. (2006) ‘Factors influencing information needs among cancer patients: A meta-analysis'. Library & Information Science Research. Volume 28 (1). 7-23. DOI: https://doi.org/10.1016/j.lisr.2005.11.003

Astin, F., Closs, S.J., McLenachan, J., Hunter, S., Priestley, C. (2008) ‘The information needs of patients treated with primary angioplasty for heart attack: an exploratory study’. Patient Educ Couns. 73(2):325-332.

Attai, D.J., Cowher, M.S., Al-Hamadani, M., et al. (2015) ‘Twitter social media is an effective tool for breast cancer patient education and support: patient-reported outcomes by survey’. Journal of Medical Internet Research. 17. Pp188

Borgermans, L., Marchal, Y., Busetto, L., Kalseth, J., Kasteng, F., Suija, K., et al. (2017) ‘How to Improve Integrated Care for People with Chronic Conditions: Key Findings from EU FP-7 Project INTEGRATE and Beyond’. Int J Integr Care. Sep 25;17(4):7.

Bugshan, H., Hajli, N., Lin, X., Featherman, M. and Cohen, I. (2014). ‘Social media for developing health services’. Qualitative Market Research. 17:3.

Burns, T., Fernandez, R., Stephens, M. (2015). ‘The experiences of adults who are on dialysis and waiting for a renal transplant from a deceased donor: a systematic review’. JBI Database System Rev Implement Rep. 13(2):169-211.

Coulter, A., Ellins, J. (2007). ‘Effectiveness of strategies for informing, educating, and involving patients’. BMJ. 335(7609):24-27.

Davies, N.J. (2010). ‘Improving self-management for patients with long-term conditions’. Nurs Stand. 24(25):49-56; quiz 58, 60.

Department of Health. (2013). ‘The Mandate: a mandate from the Government to the NHS commissioning board: April 2013 to March’. London, United Kingdom. URL: https:/ /assets. publishing.service.gov.uk/ government/ uploads/ system/ uploads/ attachment_data/ file/ 256497/ 13-15_mandate. pdf [accessed 2020-11-30]

Dhar, V.K., Kim, Y. Graff, J.T. et al (2018) ‘Benefit of social media on patient engagement and satisfaction: Results of a 9-month, qualitative pilot study using Facebook’. *Surgery*. 163:3. Pp 565 – 570. Doi: https://doi.org/10.1016/j.surg.2017.09.056

Elo, S., & Kyngäs, H. (2008). The qualitative content analysis process. Journal Of Advanced Nursing, 62(1), 107-115. doi: 10.1111/j.1365-2648.2007.04569.x

Glasgow, R.E., Nelson, C.C., Kearney, K.A., Reid, R., Ritzwoller, D.P., Strecher, V.J., et al. (2007) ‘Reach, engagement, and retention in an Internet-based weight loss program in a multi-site randomized controlled trial’. J Med Internet Res. 9(2):e11

Harrison, D.E., Galloway, S., Graydon, J.E., Palmer-Wickham, S., Rich-van der Bij, L. (1999) ‘Information needs and preference for information of women with breast cancer over a first course of radiation therapy’. *Patient Educ. Couns.* 38. pp. 217-225

Hepworth M, Harrison J. (2004). A Survey of the Information Needs of People with Multiple Sclerosis. *Health Informatics Journal.* 10(1):49-69. doi:10.1177/1460458204040668

Kaplan A. M., Haenlein M., (2010), "Users Of The World, Unite! The Challenges And Opportunities Of Social Media", Business Horizons, Vol.53, Issue 1.

Kata, A. (2012) 'Anti-vaccine activists, Web 2.0, and the postmodern paradigm–an overview of tactics and tropes used online by the anti-vaccination movement'. *Vaccine*, 30 (25) pp. 3778-3789.

Kidney Care UK (2020) https://www.kidneycareuk.org/news-and-campaigns/facts-and-stats/ [accessed 21 January 2021]

Kingod, N., Cleal, B., Wahlberg, A., Husted, G.R. (2017). ʻOnline Peer-to-Peer Communities in the Daily Lives of People With Chronic Illness: A Qualitative Systematic Reviewʼ. Qual Health Res. 27(1):89-99.

Lambert, S. D., & Loiselle, C. G. (2007). Health Information—Seeking Behavior. *Qualitative Health Research*, *17*(8), 1006–1019. https://doi.org/10.1177/1049732307305199

Lorig, K.R., Sobel,D.S., Ritter, P.L., Laurent, D. and Hobbs, M. (2001) ʻEffect of a self-management program on patients with chronic diseaseʼ. *Effective Clinical Practice.* 4(6). 256-62

Merolli, M., Gray, K., Martin-Sanchez. F. (2013). 'Health outcomes and related effects of using social media in chronic disease management: a literature review and analysis of affordancesʼ. J Biomed Inform. 46(6):957-969

National Information Board. (2014). ʻPersonalised Health and Care 2020ʼ. United Kingdom. URL: https://assets. publishing.service.gov.uk/ government/ uploads/ system/ uploads/ attachment_data/ file/ 384650/ NIB_Report. pdf [accessed 2018-11-30]

NHS England. (2014). ʻFive year forward view. ʼLondon. URL: https://www.england.nhs.uk/wp-content/uploads/2014/10/5yfv-web.pdf [accessed 2018-11-30]

O'Brien, H. L. and Toms, E. G. (2008) What is User Engagement? A Conceptual Framework for Defining User Engagement with Technology, Journal of the American Society for Information Science and Technology, 59 (6), 938–955. doi:10.1002/asi.20801

Ormandy, P. (2008) Information Topics Important to Chronic Kidney Disease Patients: a systematic review, Journal of Renal Care, 34 (1), 19–27. doi:10.1111/j.1755-6686.2008.00006.x

Ormandy, P. (2011). 'Defining information need in health - assimilating complex theories derived from information science'. Health Expect. 14(1):92-104.

Putnam, R. (2000). 'Bowling Alone: The Collapse and Revival of American Community'. New York: Simon and Schuster.

Sawesi et at (2016) ʻThe Impact of Information Technology on Patient Engagement and Health Behavior Change : A Systematic Review of the Literature Corresponding Author ʼ:, JMIR Medical Informatics. 4. doi: 10.2196/medinform.4514.

Smailhodzic, E., Hooijsma, W., Boonstra, A. et al. (2016). ʻSocial media use in healthcare: A systematic review of effects on patients and on their relationship with healthcare professionalsʼ. BMC Health Serv Res. 442. https://doi.org/10.1186/s12913-016-1691-0
Thackery, R. Crookston, B.T., West, J.H. (2013) 'Correlates of health-related social media use among adults. ʼJournal of Medical Internet Research. 15. Pp21.

Timmins, F. (2006), Exploring the concept of ‘information need’. International Journal of Nursing Practice, 12: 375-381. doi:10.1111/j.1440-172X.2006.00597.x

Van De Belt, T.H., Engelen, L., Berben, S.A., Schoonhoven, L. (2010). ‘Definition of Health 2.0 and Medicine 2.0: a systematic review’. J Med Internet Res. 12(2):e18.

Vasilica C.M., Brettle, A., Ormandy, P. (2020). ‘A Co-Designed Social Media Intervention to Satisfy Information Needs and Improve Outcomes of Patients With Chronic Kidney Disease: Longitudinal Study’. JMIR Form Res. 4(1):e13207 doi:10.2196/13207

Vasilica, C. (2015) Impact of Using Social Media to Increase Patient Information Provision, Networking and Communication (PHD thesis). University of Salford.

Vasilica, C., Oates, T., Clausner, C., Ormandy, P., Barratt, J., & Graham-Brown, M. (2021). Identifying Information Needs of Patients With IgA Nephropathy Using an Innovative Social Media–stepped Analytical Approach. Kidney International Reports, 6(5), 1317-1325. doi: 10.1016/j.ekir.2021.02.030

Vasilica, C., Ormandy, P. (2017). ‘Methods for studying information provision, networking and communication in patient support groups’. In: Urquhart, C., Tbaishat, D., Yeoman, A., editors. (2017). *Information Systems: Process and practice*. London: Facet Publishing:205-233.

World Health Organization. (2007). ‘People-Centred Health Care’. Geneva. URL: http:/ /www. wpro.who.int/ health services/ people at the centre of care/ documents/ ENG-PCIPolicyFramework.pdf [accessed 2020-12-18]

World Health Organization. (2011). ‘Noncommunicable diseases – Country profiles 2011’. Geneva. URL: https://apps.who.int/iris/bitstream/handle/10665/44704/9789241502283 eng.pdf?sequence=1 [accessed 2020-11-30]

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