

Institution: University of Salford		
Unit of Assessment: 3		
Title of case study: Improving practice in maternity care and chronic kidney disease through social media		
Period when the underpinning research was undertaken: March 2007 – December 2020		
Details of staff conducting the underpinning research from the submitting unit:		
Name(s):	Role(s) (e.g. job title):	Period(s) employed by submitting HEI:
Prof. Alison Brettle	Professor of Health Information & Evidence Based Practice	October 1997 – Present
Dr Lesley Choucri	Senior Lecturer in Midwifery	May 1998 – Present
Prof. Ben (Brian) Light	Professor of Digital Media	October 1999 – December 2013; June 2016 – Present
Dr Rose McCarthy	Assistant Director of Health	April 2010 – Present
Prof. Paula Ormandy	Professor of Long-Term Conditions	December 1998 – Present
Dr Cristina Vasilica	Lecturer in Digital Health & Society	September 2015 – Present
Period when the claimed impact occurred: August 2013 – December 2020		
Is this case study continued from a case study submitted in 2014? N		
1. Summary of the impact		
<p>Limited NHS resources require innovative approaches to healthcare. Research at Salford has led to the development of two digital interventions that respond to this environment and each one has been especially valuable during the COVID-19 pandemic. Facemums is the world's first professionally moderated social media platform to meet the information and support needs of pregnant women. The Kidney Information Network (KIN) is an award-winning digital platform that provides chronic kidney disease patients with the advice and assistance required to manage their condition. In both cases, the platforms improved users' understanding and awareness about their health, facilitated greater self-management of their health and wellbeing and enhanced overall health and wellbeing outcomes. Additional benefits include changes to professional attitudes, skill sets and service delivery, enabling NHS Trusts to effectively adapt the models and increase support provision in response to the pandemic.</p>		
2. Underpinning research		
<p>Due to the proliferation of internet-enabled devices and downloadable apps, digital media has been positioned as having the ability to transform the health and wellbeing of the UK population. For instance, the role of digital has been written into key policy documents such as the NHS Long Term Plan (2019) which advocates for its use in relation to services and health information. Salford's interdisciplinary programme of work, combining health information research, clinical knowledge and social media contributes to this agenda. The research underpinning this case study is based on the work of a well-established team of researchers: Ormandy and Brettle (UoA34) have worked together since 2006, examining how to improve patient care through the use of health information. Ormandy has worked with Light (UoA34) and Vasilica (UoA34) in the social media and health domain since 2009. In 2013, Ormandy, Vasilica and Brettle began a collaboration on the Kidney Information Network (KIN). In 2015, a collaboration was established between Choucri, McCarthy, Ormandy and Brettle for Facemums, with Light joining in 2018.</p>		
Informing and engaging in a health context		
<p>Brettle and Ormandy examined how health information was used by clinicians to influence and improve patient care [3.1]. Ormandy recognised that patient information needs are contextual</p>		

and differ over time and her work provides a conceptual framework to guide healthcare practitioners on how to meet the information needs of patients in practice [3.2]. The strongest information needs for kidney patients were in the area of self-management [3.3]. Light and Ormandy's research funded by the NHS Cancer Screening programme [3.4] combined this knowledge on patient information needs [3.2] and social media [3.5] to consider the role of social media in educating women in the area of cervical screening. This showed how to engage people with sensitive health issues online (by combining informality with evidence); principles adopted in later projects [3.6, 3.7].

Understanding the uses of social media

Light's work explored why and how people choose to connect and disconnect with social media generally and in the context of health specifically [3.4, 3.5]. This work provided insights into how people perceive their own and others' actions in these spaces (especially in relation to levels of acceptability, morality and quality of information) and governance issues associated with big data and social media. It further illustrated the complexity of different user perspectives where service users, professionals and other stakeholders are involved in health-related social media practice [3.5]. This research was applied to how people could be engaged, informed and supported about their health and wellbeing in Facemums and KIN.

Effects on health and wellbeing outcomes

Vasilica, Brettle and Ormandy's work has shown that patients who engaged with KIN understood their condition better and how to live with it, discovered alternative treatment options and developed self-management strategies [3.7]. These patients improved their self-efficacy and psychological and social outcomes regardless of the extent to which they had engaged with the platform [3.7]. Drawing upon an analysis of Facemums, Brettle, Choucri, McCarthy and Ormandy further demonstrate that social media can provide a convenient, accessible, safe and valid means of meeting the information and support needs of pregnant women when midwives provide evidence-based information and moderate the site [3.6]. Crucially, they show that relational continuity can be achieved [3.6], indicating the value of using social media to improve health outcomes in maternity care.

3. References to the research

3.1. Brettle, A., Hulme, C., & Ormandy, P. Effectiveness of information skills training and mediated searching: qualitative results from the EMPIRIC project, *Health Information & Libraries Journal*, 2007. 24(1), 24-33. <https://doi.org/10.1111/j.1471-1842.2007.00702.x>

3.2. Ormandy, P. Defining information need in health - assimilating complex theories derived from information science, *Health expectations*, 2011. 14(1): 92-104. <https://doi.org/10.1111/j.1369-7625.2010.00598.x>

3.3. Ormandy, P. and C. Hulme, Measuring patients' preferences and priorities for information in chronic kidney disease, *Information Research*, 2013. 18(3): paper 588. <http://InformationR.net/ir/18-3/paper588.html>

3.4. Light, B. and Ormandy, P. Digital and Social Media: impacts and potentials for cervical screening awareness. 2013: Salford, UK. Report available at: http://usir.salford.ac.uk/id/eprint/30646/1/Light_Ormandy_Digital_and_Social_Media_in_Cervical_Screening_Report_26_11_13.pdf

3.5. McKee, A., Albury, K., Burgess, J., Light B., Osman, K. and Walsh, A. (2018) Locked down apps versus the social media ecology: Why do young people and educators disagree on the best delivery platform for digital sexual health entertainment education? *New Media and Society* 20(12), 4571-4589. <https://doi.org/10.1177/1461444818778255>

3.6. McCarthy, R. G. Byrne, A. Brettle, L. Choucri, P. Ormandy and J. Chatwin. Midwife-moderated social media groups as a validated information source for women during pregnancy, *Midwifery*, 2020. Volume 88 (Sept). <https://doi.org/10.1016/j.midw.2020.102710>

3.7. Vasilica, C.M. A. Brettle, and P. Ormandy, A co-designed social media intervention to satisfy information needs and improve outcomes of patients with chronic kidney disease: Longitudinal study, *JMIR Formative Research*, 2020. 4(1): p. e13207. <https://doi.org/10.2196/13207> (REF2)

A total of GBP1,311,000 funding is associated with the research, including grants from NHS related bodies (approximately GBP200,000 NHS Cancer Screening Programme; GBP850,000 Health Education England) and GBP168,000 from national kidney charities/NHS organisations.

4. Details of the impact

Seeking innovative, more effective approaches to care, the NHS is looking towards digital media as one possible solution. Salford's research has benefitted two distinct areas of health care, namely the provision of maternity care and the management of chronic kidney disease (CKD), using accurate and evidence-based health information via online digital media.

Facemums involves two midwives (Facewives) moderating private Facebook groups to support women during their pregnancy (Facemums). Up to 25 Facemums are in a group, provided with information, guidance and support by the midwives, as well as each other. Following a pilot in 2015, the service was rolled out in 2018 to 568 women and 79 midwives, across 12 NHS Trusts in Cheshire, Greater Manchester, Lancashire, Merseyside, Warwickshire and West Yorkshire.

KIN provides peer-to-peer information and support for those living with CKD. Established in 2013 as the Greater Manchester Kidney Information Network (GMKIN), a service for Cheshire and Merseyside was added in 2019 (CaMKIN) and the network name of KIN was introduced in 2019. As of 31 December 2020, KIN supported 684 patients using private Facebook groups.

4.1. Greater understanding and awareness regarding health

Facemums: The Deputy Chief Midwifery Officer at NHS England stated that Facemums *'improves communication and knowledge as well as empowering women to determine the choices they wish and need'* [5.1]. Midwives made 64% of posts to the Facebook groups, mostly relating to information sharing and awareness raising at appropriate points in the pregnancy journey [5.2]. Topics covered included baby development, accessing maternity leave, how to deal with conditions such as cramps, inducing labour and expressing milk. Guidance was also given around diet, smoking, exercise and alcohol consumption [5.2]. The Head of Midwifery at South Warwickshire NHS Foundation Trust confirms that Facemums *'has provided a 24 hour online support service for pregnant women, giving them access to accurate, timely and professionally informed information'* not previously available [5.3]. 96% of pregnant women in the group reported that it improved their access to information and advice [5.2]. One woman after her first pregnancy stated: *'The Facewives shared so much information on pregnancy and labour, and it really prepared me for giving birth and it made me feel much less anxious'* [5.4].

KIN: A Consultant Nephrologist at the Salford Royal Foundation Trust testifies that KIN represents *'a fantastic advance in enabling communication with renal patients'* and that: *'it has provided an invaluable forum in which patients can express their views, learn what others are thinking, and to gain advice on how to deal with issues'* [5.5]. This view was reinforced by KIN users, for example *'when it comes to living with kidney disease, you can't beat speaking to other kidney patients'* [5.5] and *'it is really great to talk to others that have got experience of it. That have been through what I have'* [5.6, 0.40m]. As KIN was patient led, the information sharing was among peers. Posts in the Facebook groups included reassurance on why you get a headache after dialysis, stopping passing urine, avoiding certain medication and weight gain: all of this increased knowledge facilitated self-management [5.2].

4.2. Improved self-management of health and wellbeing

Facemums: Although this platform was moderated by midwives, usage data reveals there were **significant levels of self-management** evident in the interactions of pregnant women. 43% of posts involved the Facemums seeking advice from the group [5.2]. These interactions included questions regarding preparing for a scan, unexpected physical changes and queries about local services. Crucially, by answering these requests, Facemums and Facewives allowed the pregnant women to **manage their health better**. Additional posts referred to general wellbeing considerations such as how everyone in the group was doing, or targeted tagging of group members with information that might be relevant to them. In response to posts (irrespective of whether a midwife or pregnant woman made the original post), pregnant women were a significant voice in the resulting comments and reactions [5.2]. 76% of comments were made by pregnant women with a significant proportion concerning expressing care and support for others in the group, with *'how are you feeling'*, *'how you get on'*, *'keep an eye on'* and *'sorry to hear*

that and the offer of 'kisses' 'x/xx' being used in 50% of these responses [5.2]. Topics covered in these exchanges included antenatal care, baby kit (such as carriers, cots etc), blood, pain and discomfort, sleep and stress. This support, which facilitated self-management by **helping women make informed choices and establish realistic goals** for pregnancy and childbirth, was possible out of hours, with 61% of interactions overall occurring outside normal service hours of 9am to 5pm, with 58% of these being by Facewives and 63% by Facemums [5.2].

KIN: The Deputy Network Nurse at the Royal Liverpool and Broadgreen NHS Trust has said of KIN, that *'having information from someone that has lived the experience is more powerful than coming from a nurse or doctor'* [5.5]. Using KIN, patients shared **290 blogs** of their experiences, on topics such as managing depression, healthy eating and stories of diagnoses [5.2]. Usage data from the Facebook groups highlights interactions that include the provision of support (e.g. expressing sorrow at bad news or advising others to take care) and encouragement (e.g. offering people good luck with procedures and expressing positive sentiment when it went well) [5.2]. Facebook group conversations also emulated blog themes, covering topics such as healthy eating, managing depression and managing different symptoms [5.2]. This information and support provided **better coping outcomes** and **helped patients live with their condition** [5.2]. Self-management was also possible out of hours, with 51% of interactions occurring outside normal service hours of 9am to 5pm. KIN has **reduced pressure on NHS services** due its ability to support the self-management of conditions [5.7]. A Deputy Network Nurse at one NHS Trust attests that KIN *'can also offer patients emotional support, which is not something we can really offer as clinicians'* [5.6, 0.55m] and a Senior Renal Dietitian notes that KIN can offer patients support for all the different areas and aspects that CKD brings to it [5.6, 1.30m].

4.3. Improved health and wellbeing outcomes

Facemums: The Deputy Chief Midwifery Officer at NHS England confirms that Facemums *'has a strong place in terms of improving the safety and the consistency of information, and the quality of information women receive through pregnancy'* [5.1]. This is a key component of continuity of care (an indicator of improved health outcomes for the pregnant women). 647 mothers and midwives benefitted from improved **continuity of care in terms of management, informational and relational continuity** [5.2, 5.3, 5.8]. In terms of wellbeing, comments made by Facemums demonstrated reduced feelings of social isolation (*'I could have felt so alone'*), having access to the emotional support of peers (*'other ladies in the same boat'*), reduced anxiety (*'it kept me sane when the world around me was losing its head'*, *'really prepared me and made me less anxious'*) and general social support (*'it meant I had friends out there'*, *'I was comfortable sharing my feelings with others'*, *'provided a feeling of community'*) [5.4].

KIN: Patients shared aspects of their day, funny comments, good and bad experiences and feeling low in mood (which stimulated a response, emotional and peer support and immediate understanding which provided reassurance that people care) [5.2]. This **reduces social isolation**, makes people feel useful again, **reduces anxiety, increases self-confidence** and **provides support** for family members [5.2]. The social capital benefit is also evident, with one kidney patient stating that: *'My work within GMKIN [KIN] led directly to me gaining paid employment for the first time in over 10 years'* and another moderator has also secured employment at Kidney Care UK (KCUK) [5.5, 5.9].

4.4. Changed attitudes leading to new capacity and preparedness

Facemums: Trusts with Facemums services used their new-found digital literacies to adapt the model as a COVID-19 response, enabling **information and support provision to be increased from 568 to 14030 women** [5.3, 5.8]. This included **digitally upskilling shielding midwives** to enable them to run health information and parent education groups and non-clinical midwifery staff, so they could manage large Facebook groups. Former Facewives and Facemums also worked collaboratively to **establish new COVID-19 specific groups** and the associated training [5.3, 5.8]. Notably at one trust, the Facebook groups **continued following the maternity period** and Health Visitors entered the groups to provide ongoing support for the new mothers [5.8]. Furthermore, the safe private Facebook groups, moderated by midwives, have encouraged the development of small **communities of practice with mutual trust and learning** [5.2]. Facewives have also reported increased understanding of evidence across the pregnancy continuum; preparation for promotion; increased knowledge from answering

questions which translated into improved clinical practice; and achievement of continuity of care [5.2]. Facemums offers a **sustainable continuity of care model** providing a previously unmet need [5.2]. During the COVID-19 pandemic, when traditional antenatal care and support was suspended nationwide, according to pregnant women, Facemums *'provided a complete lifeline in lockdown'* and *'made things a lot more bearable due to the pandemic'* [5.4]. The service facilitated conversations relating, for example, to the availability of services, the problems of having to be socially distant from family and newborns, and the sharing of evolving policy around pregnancy and the pandemic.

KIN: KIN empowers patients and improves their capabilities which facilitates an **effective and efficient partnership with health professionals** [5.2]. In consultation with patients via KIN, a **new online Renal Dietician-run service has been set up** [5.7]. KIN has become a vital platform for **online support during the COVID-19 pandemic** as those with CKD are clinically extremely vulnerable and need to shield [5.2, 5.7, 5.9]. Support has included providing clarity regarding NHS policy and processes when having treatment and managing family and lifestyle issues when shielding [5.2]. Because of the two-way communication KIN affords, it has **reduced waiting times** during the pandemic and problems regarding medication delivery have been resolved [5.7]. KCUK used KIN as an **additional mode of communication** with people living with CKD during the pandemic [5.9]. The techniques developed across KIN were also applied to the Facebook community of KCUK and this identified the need to pay attention to psychosocial considerations and inequitable access issues [5.2]. This work led to a University of Salford/KCUK Knowledge Transfer Partnership and the **publication of the first UK Renal Psychosocial Workforce Audit** and joint research papers to determine the impact of psychosocial care models on patient distress; work which is **shaping KCUK policy development** and feeding into the **NHS England Renal Services Transformation Plan** [5.9]. Involvement with KIN has also **impacted upon health professionals' working practices** by engaging them in online environments not normally part of their daily work and leading them to **different understandings of their role** and how, where and when they might enact it [5.6, 5.7]. A clinician at Arrow Park Hospital confirmed that being part of KIN *'gives me [...] the opportunity to see what conversations the patients are having amongst themselves, and that then gives us an insight into what's really important to the patients'* [5.6, 1.59m]. A Clinical Lead in Nephrology at the Royal Liverpool Hospital also stated: *'Undoubtedly, this platform offers opportunities for patients to raise concerns, questions and thoughts, and share tips and tricks, that they might not otherwise be able to share in a conventional clinic'* [5.6, 2.14m].

5. Sources to corroborate the impact

5.1. Recording: impact of Facemums on health outcomes (Quotes at 56m). Available at: <https://eu-iti.bbcollab.com/recording/5de1c45100c34e33b11f0225d1cb5a39> (4.1-4.2)

5.2. Report: validation of Facemums and KIN projects (February 2021), confirming findings and data generated by the Facemums and KIN digital platforms and user-reported surveys (4.1-4.4)

5.3. Testimonial: Head of Midwifery, South Warwickshire NHS Foundation Trust (February 2021), on the impact of Facemums as a local service, improved confidence among midwives and broader influence on their provision during the pandemic (4.1, 4.3, 4.4)

5.4. Video: Facemums and Facewives experiences (September 2020). Available at: <https://www.facebook.com/Facemums1/videos/327087768620100> (4.1, 4.3, 4.4)

5.5. Written Testimonies: patients and practitioners on the KINET site. Available at: <https://kinet.site/gmkin/> and <https://kinet.site/camkin/> [see impact sections] (4.1-4.3)

5.6. Video: patient and practitioner experiences of KIN [Quotes at 0.40, 0.55, 1.30, 1.59 and 2.14m]. Available at: https://www.youtube.com/watch?v=FrB_OajLusQ (4.1, 4.2, 4.4)

5.7. Testimonial: Deputy Divisional Medical Director, Royal Liverpool University Hospital (February 2021), on the impact of Facemums as a local service, improved confidence among midwives and broader influence on provision during the pandemic (4.2, 4.4)

5.8. Testimonial: Deputy Chief Midwifery Officer for England, NHS England and NHS Improvement (February 2021), on the impact of Facemums as a service, its links to national policy and its broader influence on other provision during the pandemic (4.3, 4.4)

5.9. Testimonial: Kidney Care UK (February 2021), on the impact of KIN as a service, on KCUK's practice, links to national policy and use as a two-way communication channel (4.3, 4.4)