

Institution: The University of Salford
Unit of Assessment: A3 Allied Health Professions, Dentistry, Nursing and Pharmacy
Title of case study: Meeting patients' information needs to improve health outcomes
<p>1. Summary of the impact</p> <p>Research in the area of meeting patients' information needs to improve health outcomes is concerned with improving the effectiveness of information in support of improving people's health in a range of areas, demonstrating the following impact:</p> <ul style="list-style-type: none"> • The development of user responsive health information and enhanced use of digital media by healthcare providers; • Increased patient involvement in their health care leading to better health outcomes; • The development of evidence informed policy and strategy focused on patients' information needs.
<p>2. Underpinning research</p> <p>The key researchers and positions they held at the institution at the time of the research are as follows: Dr Paula Ormandy (from 1998), Member of School of Nursing, Midwifery and Social Work (from 2006) and Professor Ben Light (from 2009) School of Arts and Media. Building on a theoretical and empirical foundation of identifying, developing services to meet patients' information needs, and equipping health professionals with the skills to engage patients in their own health management, <i>Meeting patients' information needs to improve health outcomes</i> focuses on using information more effectively in managing long-term conditions and public health. The impact of this case study is underpinned by the following research:</p> <ul style="list-style-type: none"> • 2006-2007: <u>Identifying chronic kidney disease (CKD) patients' priorities and preferences for information topics</u>: funded by the British Renal Society and in partnership with Salford Royal NHS Foundation Trust, the University of Manchester and a Patient Advocate, identified the information preferences and priorities for CKD patients. Generating an evidence base for information provision, exposing the contextual influences of information need, Ormandy extended the working definition of information need, developing a conceptual framework to guide healthcare practitioners when meeting patient information priorities in practice. • 2011-2012: <u>Shared Decision-making Project in Renal Services</u>: funded by National Kidney Care and in partnership with Salford Royal Foundation NHS Trust, Ormandy was co-opted as an expert advisor to guide the implementation of a patient-led approach to information sharing models, empowering patients to identify their readiness to accept condition specific information. The project introduced motivational interviewing training to increase clinicians' engagement skills, implemented a shared-decision making agenda, and evaluated shared-decision making between patients and health professionals, developing a cultural change from a paternalistic to a collaborative working approach. • 2009-2011: <u>Facilitating the engagement of boys and young men in sexual health using new media</u>: funded by a Knowledge Transfer Partnership, Technology Strategy Board, the Economic and Social Research Council and in partnership with Brook Manchester, Light and Ormandy harmonised client and clinic activity data to improve management information, developing a clear evidence base. The project implemented new-media services to engage boys and young men in the maintenance of their sexual health, including an education App for iPods to deliver sexual health education focused on condom use; an on-line 'chat room' for sexual health advice; and staff training regarding the use of digital media. It integrated evaluation methods to align service delivery with outcomes and created an evaluation and guidance toolkit for practitioners using digital media. • 2010-2011: <u>Lesbian, Gay & Bisexual (LGB) Women in the North West: a multi-method study of cervical screening attitudes, experiences and uptake</u>: funded by the Department of Health National Cervical Screening Programme and in partnership with the Lesbian and Gay Foundation, a 12 month digital media campaign to increase awareness and uptake

among LGB women was implemented ([Are you ready for your screen test?](#)), Light and Ormandy identified reasons why women don't engage with cervical screening, finding that myths and lack of accurate information influenced women's decisions as to engagement, and evaluated the digital media campaign, measuring the impact of digital media interventions to effect behaviour change.

- **2012-2013: Promoting Cervical Screening in the North West: A Digital Media Based Approach** funded by the NHS Executive, Ormandy and Light conducted a multifaceted digital campaign to address issues facing 24-29 year old women with respect to their knowledge of cervical cancer and confidence in the uptake of cervical screening, The campaign was inspiring through offering many ways for women to engage and educate each other via [website](#), [Facebook](#), [Twitter](#), [Pinterest](#), and [YouTube](#). This approach allowed women to create share and access campaign materials, and key health messages on their terms, rather than through traditional didactic health promotion methods.

3. References to the research

Key Outputs

1. Ormandy P, Hulme CT, Caress AL, Macdonald J, O'Donoghue D, Crane D. 2007. *Identifying chronic kidney disease patients' priorities and preferences for information topics*. Salford Centre for Nursing, Midwifery and Collaborative Research, Institute for Health and Social Care Research, University of Salford. Report, April: ISBN 9781905732265. Report for British Renal Society
2. Ormandy P. 2008a. *Information topics important to chronic kidney disease patients: a systematic review*, Journal of Renal Care, Mar; 34(1): 19-27, [DOI \(REF2\)](#)
3. Ormandy, P. 2008b, *Chronic kidney disease: Patient information needs, preferences and priorities*, PhD Thesis, University of Salford. [URL](#)
4. Ormandy P. 2011. *Defining information need in health – assimilating complex theories from Information Science*. Health Expectations, 14(1): 92-104, [DOI](#).
5. Light B, Ormandy P. 2011. *Lesbian, Gay & Bisexual Women in the North West: A multi-method study of cervical screening attitudes, experiences and uptake*. Lesbian & Gay Foundation and University of Salford Report, July: ISBN 9781907842139. Report for the Department of Health Cervical Screening Programme. **(REF2)**
6. Vasilica CM, Ormandy P, Light, B. 2013. *Delivering and measuring the impact of digital media: Evaluation toolkit*. KTP Project Report, University of Salford.
7. Ormandy P, Hulme C. 2013. *Measuring patient preferences and priorities for information*. Information Research. [URL \(REF2\)](#)
- 8.

Key Grants

9. **2006-2007: Identifying chronic kidney disease (CKD) patients' priorities and preferences for information topics**. P Ormandy, C Hulme with J Macdonald, D O'Donoghue (Salford Royal NHS Foundation Trust), AL Caress (University of Manchester), D Crane (Patient Advocate). Funding: British Renal Society, £26,986
10. **2009-2011: Facilitating the engagement of boys and young men in sexual health using new media**. B Light, P Ormandy with S Mallas (Brook Advisory Clinic, Manchester). Funding Body: Knowledge Transfer Partnership – Technology Strategy Board, Economic and Social Research Council, £120,000. Finalist, Brook National Innovation Award 2011.
11. **2010-2011: Lesbian, Gay & Bisexual (LGB) Women in the North West: a multi-method study of cervical screening attitudes, experiences and uptake**. B Light, P Ormandy with R Cookson, A Emery (LGF). Funding Body: Department of Health National Cervical Screening Programme, £108,000. Winner, Jo's Cervical Trust Award 2011.
12. **2012: Impact of using social media to increase patient information provision, networking and communication**, P Ormandy, C Vasilica, K Pennington (Patient) Funding Body: British Renal Society, £16,745.00.
13. **2012-2013: Promoting Cervical Screening in the North West: A Digital Media Based Approach**. P Ormandy, B Light. Funding Body: Department of Health North West Cervical Screening Quality Assurance Reference Centre (£75,000), and Heywood, Middleton and

Rochdale PCT (£25,000) total budget £100,000

4. Details of the impact

The development of evidence informed policy and strategy focused on patients' information needs:

- **2008, 2011-2012:** Directly informing national guidelines in patient management, research findings by Ormandy et al. identified the key information needs preferences and priorities for people with CKD in the UK. The National Collaborating Centre for Chronic Conditions used these findings to guide NICE recommendations for healthcare practitioners on what to consider when meeting the information needs of people with CKD in practice settings: (NICE 2008: p181-182) <http://guidance.nice.org.uk/CG73/Guidance/pdf/English>
- Ormandy led a workshop for the Department of Health Senior Renal Advisory Group on patient engagement to enhance the skills of health professionals. As an expert advisor Ormandy, in partnership with Salford Royal Foundation NHS Trust, assisted clinicians to secure funding from National Kidney Care for a local shared decision-making project in clinical practice. This project implemented a patient-led approach to information provision through introducing agenda setting within clinics, improving patient confidence to make clear their information needs within consultations to facilitate decision making.
- In partnership with the local Kidney Patients Association, to facilitate improved information provision, Ormandy & Vasilica (PhD student) secured grant funding in 2013 to develop a user-led online digital and social media CKD information hub, tailored to meet the needs of patients by patients, using digital and social media to facilitate patient information provision, networking and communication for people with CKD. This network is established and patients are generating and adding content, www.qmkin.org.uk

The development of user responsive health information and enhanced use of digital media by healthcare providers:

- **2009-2011:** The deployment of digital media for sexual health education is extensive, however many interventions are undertaken in the absence of methods for impact evaluation. The Brook sexual health education through digital media KTP project, developed digital media based interventions embedded with evaluation mechanisms to continually assess the impact and the value of interventions in practice. Client and clinic activity data naturally occurring within the different Brook services was harmonised to allow the generation of regular reports, numbers of young people targeted, activity undertaken, as a clear evidence base of sustained activity to provide for potential increase in uptake of initiatives. The ethos of the service shifted to understanding what works, why and how they could do things differently, as a result of the embedded evaluation training deployed across the organisation.
- The KTP improved engagement with the free condom service for boys through digital media (iPod, videos). [The Condom Demonstration](#) 'app' provides a mechanism for educating a wider population on condom use, whilst gathering automated data through a reporting system on the use of the app, ethnicity of people that use it, and capturing behavioural changes. The condom demo 'app', was nominated for a Brook 2011 National Innovation Award and shortlisted as a finalist, and publicised by the BBC where it was promoted on the Radio (by Light and Vasilica). The 'app' is available through the national organisation website and the iPhone App store. The outcomes of the KTP have been taken up nationally with Brook National extending trials of a Web 2.0 based community site.
- Knowledge has been exchanged throughout Brook as the project progressed leading to a significant cultural change locally enabling Brook National staff to lead the way in accessible social media sexual health education, securing a Department of Health Virtual Health project (£170K), increasing the organisation's ability to secure new service contracts in an increasingly competitive environment.

Increased patient involvement in their health care:

- **2010-2011:** The "Are You Ready For Your Screen Test?", initiative, which included humorous short films on You Tube based on blockbuster movies like Star Wars, Love Actually and Dirty Dancing, was launched by the Lesbian and Gay Foundation in

partnership with the University of Salford and funded by the NHS Cervical Screening Programme. The campaign used YouTube films, booklets, posters and radio, print, online and social media advertising and information with the Hollywood theme and had a massive impact. Analysis of the 12 month North West campaign was undertaken by Ormandy and Light and findings from the 1,000 women surveyed included;

- Only 49% of respondents of an eligible age (25-64) had been for a cervical screening test within NHS recommended time scales, rising to 73% post-campaign;
- 51% reported some form of positive behaviour change as a result of the campaign;
- 96% felt that the campaign was effective.
- The Lesbian & Gay Foundation's campaign encouraging women not to ignore a test which could mean the difference between life and death earned the Manchester-based group top billing in the Jo's Cervical Cancer Trust 2011 Cervical Screening Awards.
- **2012-2013: Promoting Cervical Screening in the North West: A Digital Media Based Approach** engaged women in the 24-29 age group and has embedded evaluation mechanisms throughout to constantly audit its performance, and adjust its methodology to maximise its impact. The [campaign](#) is improving this age group's awareness, knowledge and confidence in cervical screening. Starting from a zero base in March 2013, in terms of community/network, to date the campaign website has received over 3000 unique views, Facebook has 2200 likes with an associated audience of over 120,000 and our YouTube videos have had almost 9500 views. Over 450 women have completed our evaluative survey and our initial analysis is that 82% report that they think the campaign is effective, 50% report that it has had a positive effect on their knowledge, confidence or behaviour, 45% reported no change as they already went for screening.

5. Sources to corroborate the impact

- a) **Programme Manager at the Lesbian and Gay Foundation:** "Countless lives have been put at risk for years because of the myth that lesbian and bisexual women don't need cervical screening. Cervical cancer claims the lives of three women every day in the UK and sees a woman diagnosed every three hours, yet cervical cancer is preventable and the NHS screening programme plays a vital role in saving around 4,500 lives in England each year. But less than half of lesbian and bisexual women of eligible age surveyed in the North West had been for cervical screening during the recommended three to five years previously. The success of *Are You Ready for Your Screen Test?* highlights the overwhelming need for, and benefit of, targeted campaigns on a wider scale."
- b) **Director, NHS Cervical Screening Programme:** "We have been delighted to work with The Lesbian & Gay Foundation in Manchester and the University of Salford on a pilot programme of campaigning and information giving to see how this change of policy could be turned into real life action. This report gives an account of that pilot; records what worked and what didn't, and allows other parts of the country to learn from this exercise."
- c) **Director of Jo's Cervical Cancer Trust,** said: "I and the rest of the judges were hugely impressed with this winning application. It was innovative, creative and very well targeted. The results of this project are already proving to be very positive and of course this is a great example of best practice that can be shared with other organisations across England and the rest of the UK."
- d) **Corroboration from the Chairman of the Hope Kidney Patients Association**
- e) **Link to guidelines for the NHS by NICE, the National Collaborating Centre for Chronic Conditions** <http://guidance.nice.org.uk/CG73/Guidance/pdf/English>
- f) **Link to final report** Light, B and Ormandy, P 2011, http://ripasstseu.s3.amazonaws.com/www.lgf.org.uk/files/documents/sep_11/FENT_13_16185576_north-west-lgb-women-cervical-.pdf
- g) **Link to summary community report** http://ripasstseu.s3.amazonaws.com/www.lgf.org.uk/files/documents/sep_11/FENT_13_16185513_are-you-ready-for-your-screen-.pdf