

<b>Institution:</b> University of Warwick		
<b>Unit of Assessment:</b> UOA2 - Public Health, Health Services and Primary Care		
<b>Title of case study:</b> Understanding and Valuing Patient and Public Perspectives		
<b>Period when the underpinning research was undertaken:</b> 1 August 2007- 31 December 2020		
<b>Details of staff conducting the underpinning research from the submitting unit:</b>		
<b>Name(s):</b>	<b>Role(s) (e.g. job title):</b>	<b>Period(s) employed by submitting HEI:</b>
Professor Sophie Staniszewska	Professor	August 2007 - present
Professor Kate Seers	Professor	August 2007– present
Dr Kirstie Haywood	Reader	August 2007– present
<b>Period when the claimed impact occurred:</b> 1 August 2013- 31 December 2020		
<b>Is this case study continued from a case study submitted in 2014?</b> N		
<p><b>1. Summary of the impact</b> (indicative maximum 100 words)</p> <p>Warwick's research into patient and public involvement (PPI) has contributed to changing the way in which healthcare is researched, evaluated and improved. It has embedded the patient perspective into the development of health and social care systems, both in the UK and internationally. Research by Professor Sophie Staniszewska and colleagues from Warwick Medical School has directly shaped more than 75 NICE guidance documents, including the first national and international clinical guidelines on patient experience. Through collaboration with policy organisations, care providers, and global research organisations, the work has placed patient experience at the centre of policy-making and best practice guidance. The researchers have created new opportunities, which enable patients and the public to have a voice in the creation and dissemination of healthcare knowledge.</p>		
<p><b>2. Underpinning research</b> (indicative maximum 500 words)</p> <p>Over the past 20 years, policy organisations, care providers, and national and international research organisations have placed increasing emphasis on understanding and valuing patient experience and strengthening patient and public involvement in research. Between 2007 and 2020 researchers at the University of Warwick played a key role in the development of two interconnected streams of highly significant work that have transformed understanding of and influenced national and international strategy on patient experience and involvement:</p> <p><b>a. Patient experience</b></p> <p>Less than a decade ago, patient experience was not necessarily viewed as a key concept in the health-practice evidence base and there was no agreed evidence-based patient experience framework to inform the development of national policy and practice.</p> <p><u>Warwick Patient Experience Framework (WaPEF):</u> In 2012, Professors Staniszewska and Seers were commissioned by the Royal College of Physicians Clinical Guideline Centre to develop a unified, evidence-based framework using the concept of patient-based evidence to complement clinical and economic forms of evidence [3.1]. WaPEF is recognised as the underpinning framework for NICE guidance.</p> <p><u>Patient-reported outcomes (PROMS):</u> In October 2013, Dr Kirstie Haywood explored the potential for patient engagement in health-related quality of life (HRQL) and patient-reported outcomes (PROMS) research at an International Society for Quality of Life research (ISOQOL) symposium. The discussions recognised the need to involve patients in co-production of</p>		

PROMS and to develop a framework or toolkit of how to embed patient experience (PE) within HRQL and PROMS research.

### **b. Patient and Public Involvement (PPI)**

Staniszewska's research has underpinned the development of the international PPI evidence base, which was previously fragmented and poorly theorised, with limited understanding of PPI impact. To generate an evidence base for policy and practice [3.2], studies looked at:

How PPI works: Drawing together evidence to understand its conceptualisation, definition, impact, measurement and outcomes [3.2, 3.3, 3.4, 3.5] Staniszewska's research generated an understanding of how PPI works [3.2, 3.5]; she and colleagues used their findings to develop deeper insights into what is effective PPI within healthcare organisations, and to understand the role and experiences of patients. For example, our systematic reviews have identified a range of impacts PPI can have on research including enhancing the quality of research and the way in which individuals and communities feel valued [3.3,3.4].

What to report about PPI: Staniszewska and Seers identified the key challenge of poor-quality PPI reporting and developed internationally recognised EQUATOR guidance, GRIPP2 (an update of GRIPP - Guidance for Reporting Involvement of Patients and the Public). GRIPP2 is the first international evidence-based guidance to enhance the quality of PPI reporting and strengthen the PPI evidence base by creating transparency in the ways in which the public are involved in research [3.6].

How to enhance PPI: As Vice-chair of the NIHR PPI policy review, Staniszewska worked with colleagues in NIHR to identify the importance of co-production and contributed to NIHR guidance on co-production [3.2] and a collection of examples for practice. She led on the implementation of a co-production model of publishing to underpin the journal 'Research Involvement and Engagement' and worked with the BMJ to generate an understanding of how patients and the public experienced this way of working in publishing.

How to support global PPI practice: Warwick's active international role has provided the foundation for understanding how PPI operates across health care systems, and how HTA agencies engage with patients. Building on her decade of shaping public involvement in HTA, Staniszewska is co-editor of the first special issue of the International Journal for Technology Assessment in Healthcare with 24 papers on public involvement, due for publication in February 2021. Early papers include the importance of co-production in NICE. Patient and community representatives have been supported to publish as lead or co-authors.

### **3. References to the research** (indicative maximum of six references)

- [3.1] **Staniszewska, S; Boardman, F; Gunn, L; Roberts, J; Clay, D; Seers, K; Brett, J;** Avital, L; Bullock, I and O'Flynn, N (2014). The Warwick Patient Experiences Framework: patient-based evidence in clinical guidelines. International Journal for Quality in Health Care. Volume 26, Number 2: pp. 151–157, doi:10.1093/intqhc/mzu003.
- [3.2] **Staniszewska, S;** Denegri, S; Matthews, R; and Minogue, V; (2018) Reviewing progress in public involvement in NIHR research: developing and implementing a new vision for the future. BMJ Open, 8. e017124. doi:[10.1136/bmjopen-2017-017124](https://doi.org/10.1136/bmjopen-2017-017124)
- [3.3] **Brett J, Staniszewska, S, Mockford C, Herron-Marx S, Hughes J, Tysall C, and Suleman R** (2014) A systematic review of the impact of patient and public involvement on service users, researchers and communities, The Patient: 7(4):387-95. DOI: 10.1007/s40271-014-0065-0
- [3.4] **Brett, Jo, Staniszewska, S, Mockford, C, Herron-Marx, S, Hughes, J, Tysall, C and Suleman, R** (2012) Mapping the impact of patient and public involvement on health and social care research: a systematic review. Health Expectations, Volume 17 (Number 5). pp. 637-650. doi:[10.1111/j.1369-7625.2012.00795.x](https://doi.org/10.1111/j.1369-7625.2012.00795.x)
- [3.5] Wilson P, Mathie E, Keenan J, McNeilly E, Goodman C, Howe A, Poland F, **Staniszewska S,** Kendall S, Munday D, Cowe M, Peckham S. (2015) ReseArch with Patient and Public

invOvement: a RealisT evaluation - the RAPPORT study. Journal: Health Services and Delivery Research Volume: 3 Issue: 38 DOI: <http://dx.doi.org/10.3310/hsdr03380>.

[3.6] **Staniszewska, S**, Brett J, Simeria I, **Seers, K, Mockford, C**, Goodlad, S, Altman, DG, Moher, D, Barber, R, Denegri, S, **Entwistle, A**, Littlejohns, P, Morris, C, **Suleman, R**, Thomas, V, **Tysall, C** (2017) GRIPP2 reporting checklist: tools to improve reporting of patient and public involvement in research. BMJ 358:j3453. Doi: <https://doi.org/10.1136/bmj.j3453>

#### Grants

PI Patricia Wilson, Co I **Sophie Staniszewska**, Public involvement in research: a realist evaluation of approaches, processes and outcomes, NIHR for Health Research Health Services and Delivery Research programme, 09/2011- 02/2014, GBP300,608

PI **Sophie Staniszewska**, A Structured Review of Evidence on Conceptualisation, Measurement, Impact and Outcomes of Patient and Public Involvement in Health and Social Care Research, UKCRC, 11/2008- 11/2009, GBP58,444

#### 4. Details of the impact (indicative maximum 750 words)

##### Impact on policy and practice in the UK: measured improvements in patient experience

Staniszewska has been a member of the NICE Expert Panel (since 2018), the NICE Implementation Strategy Group (since 2018), the NICE Guidelines Centre Expert Panel (since 2019) and the NICE Implementation strategy group (since 2019). She was the invited topic advisor for the development of the Social Care Institute for Excellence guidance on a good experience of social care (SCIE 2018).

NICE Guidance: Staniszewska and Seers' were commissioned by the Royal College of Physicians Clinical Guideline Centre to develop a high quality evidence-based Warwick Patient Experiences Framework (WaPEF). This informed the first national and international clinical guideline on patient experience, 'NICE patient experience in adult NHS services: improving the experience of care for people using adult NHS services clinical guideline' [CG138] (February 2012, updated October 2015 and February 2020) and the 'NICE patient experience in adult NHS services' Quality Standard [QS15] (February 2012, updated July 2019) [5.1]. The guidance is aimed at clinical and non-clinical staff, commissioners, providers and patients, and focuses on components of good patient experiences, setting out indicators of high-quality, cost-effective care.

NHS England: Staniszewska was subsequently invited to join the National Quality Board Patient Experiences Group to inform an integrated national strategy developed by NHS England to align key agencies. NHS England National Director for Patient Experience, Neil Churchill, states: "*[Warwick's] research has created a high-quality evidence base which now underpins our national approach to improving care experiences and has made a vital contribution to creating evidence-based policy*" [5.2]. WaPEF underpinned the NHS England statement 'Improving experiences of care: Our shared understanding and ambition' to which 15 agencies signed up to the policy position from 2015, including the Department of Health, NHS England and Care Quality Commission.

Monitoring uptake of CG138 and QS15: This is routinely carried out by the Quality Health National Cancer Patient Experience Survey, Care Quality Commission National Inpatient Survey, Care Quality Commission Emergency Department Survey, NHS England GP Patient Survey, NHS Digital National Diabetes Inpatient Audit, and Royal College of Psychiatrists National Audit of Dementia. CG138 is directly referenced in 76 current NICE Guidelines, typically within a patient-centred care section stating: "*NICE has produced guidance on the components of good patient experience in adult NHS services. All healthcare professionals should follow the recommendations in patient experience in adult NHS services.*" They set out considerations regarding: communication and support; providing information/ sharing with patients, family and carers; shared decision-making; treating patients as individuals; and continuity of care. A wide range of conditions and procedures are covered, such as:

- Routine preoperative tests for elective surgery NICE guideline [NG45], with 10,100,000 operations completed by the NHS (NHS Digital, Hospital Admitted Patient Care Activity, 2015-16)
- Type 2 diabetes in adults: management NICE guideline [NG28], with over 3,400,000 adults diagnosed with type 2 diabetes in 2019 (Diabetes.org.uk)

Learning examples: The NICE Local Practice Collection published seven shared learning examples between August 2013 and July 2019 about how NICE guidance on patient experience has been implemented by local health and social care services. Common themes include: increased positive feedback from patients; increased, standardised or improved training for staff; cost savings for the NHS; reductions in re-referrals; patients feeling empowered by being involved in their own care and decision-making; patients being given the right information; patients being provided with continuity and well-coordinated care; and a decrease in complaints. For example, in 2018 Imperial College Healthcare NHS Trust used Quality Improvement tools to improve understanding of patient experience and the quality of the acute non-invasive ventilation (NIV) service for chronic obstructive pulmonary disease patients. This demonstrated that *“Thematic analysis of patient experience feedback has improved from 16% positive responses to 56% in the last year. This includes positive comments on communication, information provision and decision-making”* [5.3]. In 2013-2014, Dorset County Hospital NHS Foundation Trust used CG158 and QS15 to provide a neutral structure to categorise and theme complaints thereby identify areas of poor practice. Following implementation and staff training, *“the total number of complaints escalated to the Parliamentary and Health Service Ombudsman in 2013/14 was 1, this was an 87.5% (n=8) decrease on the previous year”* [5.3].

#### **Impact on policy, practice and public opinion: normalising PPI in research**

International connection and debate: In 2018 Staniszewska collaborated with NIHR, Cochrane, INVOLVE and COMET (Core Outcomes Measures in Effectiveness Trials) to launch the International PPI Network, a social movement with over 240 member organisations and individuals representing patients, the public, researchers, clinicians and policymakers [5.4]. Since then, an online international seminar programme has covered a wide range of topics for patients and publics. Between August 2019 and June 2020 there have been 10 webinars with 823 attendees and 3,254 views on PPI in research. Staniszewska was a member of the Steering Group and co-chair of the Methods and Impact subgroup of the Health Technology Assessment International (HTAi) Patient and Citizen Involvement Special Interest Group until June 2019. With members in 65 countries, HTAi has produced a range of resources to support public voice in HTA.

National and international strategic policy in health research: In 2015, with Staniszewska as Vice-Chair, the NIHR Breaking Boundaries Policy Review assessed progress in public involvement and develop a vision and mission for 2025. The Policy Report ‘Going the extra mile’ (NIHR 2015) and paper (Staniszewska et al, 2018) provides clear strategy and direction for NIHR, including implementation of co-production, which Staniszewska supported in development [5.5]. She was also part of the NIHR National Strategy Group which was reviewing PPI impact, and is now part of the newly formed NIHR Global Health PPI Advisory Group, in addition to informing the development of the NIHR Values Framework.

Staniszewska was an invited member of the international team developing open science and public involvement metrics on behalf of the Wellcome Trust and the Bill and Melinda Gates Foundation in 2018. A toolkit was developed to measure the implementation and impact of open science partnership for use by government and philanthropic grantors and community organisations [5.6]. Staniszewska advised colleagues and policymakers in Canada who were developing strategic PPI policy, as part of an invited international summit she attended with the NIHR National Director of PPI, and she chaired the award of Health Research Board of Ireland 2020 infrastructure funding for public involvement.

The public voice in research publishing: In 2015 Staniszewska established a new journal, Research Involvement and Engagement (RIE), which aims to develop the evidence base of PPI.

This unique co-production model has grown exponentially, from 26,902 article accesses in its first year to over 170,025 in 2020. The Journal Development Manager at BMC, states: “Other journals published by BMC and Springer Nature are drawing on Research Involvement and Engagement to strengthen patient involvement in the publishing process. Since launch, the Journal has gone from strength to strength with 2020 becoming our most successful year for publications” [5.7]. “The journal has achieved ‘Patient Included’ status and indexing in Scopus, who upon acceptance stated: ‘This is a very innovative journal on many counts, the involvement of service users/patients in all aspects of the journal content as well as the open review for accepted papers” [5.7].

The co-production approach enables patients and the public to shape published research, with researchers encouraged to work with patients as collaborators, to include patients as co-authors and to write a mandatory plain English summary [5.8]. The editors have developed a pool of patient peer reviewers (n=289) and, in collaboration with the BMJ, surveyed the patient experience of peer review in order to improve their experience. Their approach to co-production is underpinned by the NIHR guidance [5.9] that was co-authored by Staniszevska.

The journal is co-edited by patient advocate Richard Stephens, who is a survivor of two cancers and a heart emergency and has participated in four clinical trials. He first became involved in patient advocacy in 1998 when, as a newly diagnosed cancer patient, he misunderstood information about a randomised trial given to him in a patient information sheet. *“My own misunderstanding made me wonder why patients weren’t involved in writing the information that would be given to other patients. Back then, hospitals wrote their own patient information sheets. Now they are written by the research team, usually involving at least one patient as good practice.*

*“Patients should not only be at the centre of trial design, we should be present throughout the whole research process. In the UK, we are ahead of any other country in the world in this regard. We still have lots of gaps to fill but Professor Staniszevska’s work has made an important contribution to the progress that has been made to give patients a voice in the design of their own healthcare.” [5.7].*

##### **5. Sources to corroborate the impact** (indicative maximum of 10 references)

- [5.1] NICE Clinical Guidance and Quality Standard informed by Warwick research: CG138 ‘Patient experience in adult NHS services: improving the experience of care for people using adult NHS services’ (Feb 2012, updated 2015 and 2020) <https://www.nice.org.uk/guidance/cg138> and QS 15 ‘Patient experience in adult NHS services, quality standard’ (Feb 2012, updated 2019) <https://www.nice.org.uk/guidance/qs15>
- [5.2] Written statement (email) from NHS England National Director for Patient Experience.
- [5.3] NICE shared learning examples: <https://tinyurl.com/15eao5ms> and <https://tinyurl.com/5qu7y2q9>
- [5.4] Blogs raising awareness of the PPI network: <https://tinyurl.com/10qty863> (Nov 2017) and <https://tinyurl.com/136q9emq> (May 2018)
- [5.5] Guidance recommendations informed by Warwick research: NIHR ‘Going the extra mile: Improving the nation’s health and wellbeing through public involvement in research’ Final report and recommendations to Chief Medical Officer, Department of Health (2015) <https://tinyurl.com/1sqzdp6m>
- [5.6] Gold, E. Richard, Ali-Khan, Sarah E., Allen, Liz, Ballell, Lluís, Barral-Netto, Manoel, Carr, David, Chalaud, Damien, Chaplin, Simon, Clancy, Matthew S., Clarke, Patricia *et al.* (2019) An open toolkit for tracking open science partnership implementation and impact. *Gates Open Research*, 3. 1442. [doi:10.12688/gatesopenres.12958.2](https://doi.org/10.12688/gatesopenres.12958.2)
- [5.7] Written statements from Patient and Publisher
- [5.8] Research Involvement and Engagement Journal established by Warwick with Staniszevska and patient, Richard Stephens as Co-editors in Chief: <https://tinyurl.com/1qr4708q>
- [5.9] Hickey *et al* (2018) NIHR and Involve Guidance on co-producing a research project (Feb 2018) <https://tinyurl.com/27mf5xql>