

<b>Institution:</b> University of the West of England (UWE), Bristol
<b>Unit of Assessment:</b> 3 – Allied Health Professions, Dentistry, Nursing and Pharmacy
<b>Title of case study:</b> Influencing healthcare policy and practice in the field of cleft lip/palate
<b>1. Summary of the impact</b> <p>Many of the millions of people worldwide with disfigurement face significant psychological challenges. Research at UWE's Centre for Appearance Research (CAR) has made a substantial contribution to the interventions and healthcare provision available for patients with the most common congenital disfigurement - cleft lip and palate - in the UK and internationally. Specifically, our research has underpinned: (1) The inclusion of psychologists as key members of all UK cleft teams; (2) The development of effective forms of psychological support and interventions currently in use by psychologists and charities across the UK and abroad; (3) The development of evidence-based training packages currently being used by practitioners across Europe.</p>
<b>2. Underpinning research</b> <p><b>Context:</b> A cleft (gap) in the lip/palate occurs in approximately 1:700 live births. Treatment includes surgery, speech therapy, hearing and orthodontics from birth to 18 years and beyond. Until recently, healthcare provision was based on the biomedical model, focusing on optimising aesthetics (through surgery) and physical function (for example, through orthodontics).</p> <p>The <b>Research Team</b> from CAR comprises Nichola <b>Rumsey</b> (Professor of Appearance Psychology; joined UWE as a Lecturer 1990-1992; Senior Lecturer 1992-1997; Reader 1997-2002; Professor 2002-current), Diana <b>Harcourt</b> (Research Psychologist 1994-1997; PhD student 1997-2000; Lecturer 2000-2004; Senior Lecturer 2004-2006; Reader 2006-2012; Professor 2012-current), Tim <b>Moss</b> (Senior Lecturer 2000-2005; Principal Lecturer 2006-2009; Reader 2009-2012; Associate Professor 2012-current); Research Associates <b>Wyn-Williams</b> (2002-2004) <b>Garlick</b> (2002-2006) and <b>Williamson</b> (2006-2009; Research Fellow 2010-2013), PhD students <b>Feragen</b> (2006-2010) and <b>Bessell</b> (2006-2009), dissertation student Turner (1995-1996) and collaborators <b>Clarke</b> (Consultant Clinical Psychologist &amp; Visiting Research Fellow, 2002-2008; Visiting Professor 2009-current) and <b>White</b> (Senior Lecturer in Statistics, 2000-current). The team completed a series of research studies, funded in part by The Nuffield Foundation (Ref 2), the charity Changing Faces (Ref 6) and The Healing Foundation (Ref 4; G1) from 2002.</p> <p>This research highlighted the prevalence of psychological distress in children, young people and adults with cleft and other craniofacial conditions (see also Ref 1). The findings also emphasised the gap between the unmet psycho-social needs of patients and their families and the provision of healthcare at that time (Refs 1, 2 &amp; 3). We used the research results to persuade a major new funder in the field – The Healing Foundation (established under the auspices of The Royal College of Surgeons) – of the imperative of funding psychological research. This led to the award (G1) in 2005. This programme of research (G1; completed in 2009), challenged conventional wisdom by demonstrating the significant contribution made by psychological factors (as opposed to the severity or type of disfigurement) to patient outcomes (Ref 4). Instead, the research highlighted the imperative of providing appropriate psychological care and interventions throughout the treatment pathway (Ref 4).</p> <p>In parallel with these insights into the deficiencies in healthcare provision, Rumsey joined a consortium of international collaborators funded by the US NIH in a project to develop patient-centred outcome measures (Ref 5). Rumsey's key role (as the only non-US partner) was to contribute specific expertise and data relating to craniofacial conditions, including cleft, and to trial the adoption of the resulting measures by clinical teams in the UK. In addition, Rumsey and her team continued to develop evidence-based methods of offering support and interventions (e.g. Refs 4 &amp; 6) and to conduct a series of qualitative studies which have given voice to patients and their families. These studies have influenced the design of interventions (Ref 6) and research agendas of major funders in the field (The Healing Foundation Cleft Gene Bank and Cohort Studies <a href="http://www.bristol.ac.uk/dental/cleft-collective">www.bristol.ac.uk/dental/cleft-collective</a>) (G2)</p>
<b>3. References to the research</b> <p>1. Turner S, Thomas P, Dowell T, <b>Rumsey N</b> &amp; Sandy J (1997) Psychological outcomes amongst</p>

## Impact case study (REF3b)

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2. **Rumsey N**, Clarke A, White P, Wyn-Williams M & Garlick W (2004) Altered body image: Auditing the appearance-related concerns of people with visible disfigurement. *Journal of Advanced Nursing*, 48 (5), pp.443–453 <http://dx.doi.org/10.1111/j.1365-2648.2004.03227.x>

3. Feragen K, Borge A & **Rumsey, N** (2009) Social experiences in 10 year old children born with a cleft: Exploring psychosocial resilience. *Cleft Palate-Craniofacial Journal*, 46, pp.65-74 <http://dx.doi.org/10.1597/07-124.1>

4. Clarke A, Thompson A, Jenkinson, E, **Rumsey, N** & Newall (2013) CBT for Appearance Anxiety: Psychosocial Interventions for Anxiety Due to Visible Differences, Publisher: Wiley Blackwell – book

5. Patrick D, Topolski T, Edwards T, Aspinall C, Kapp-Simon K, **Rumsey N**, Strauss R & Thomas C (2007) Measuring the quality of life of youth with facial differences. *Cleft-Palate Craniofacial Journal*, 44 (5) pp.538-547 <http://dx.doi.org/10.1597/06-072.1>

6. Bessell A, Clarke A, Harcourt D, Moss T & **Rumsey N** (2010) Incorporating user perspectives in the design of an online intervention tool for people with visible differences: Face IT. *Behavioural and Cognitive Psychotherapy*, 38, pp.577-596 <http://dx.doi.org/10.1017/S1352465810000305> and <http://eprints.uwe.ac.uk/11597/>

### Key grants

**G1. Rumsey N (Principal Investigator)**, Clarke A, Harcourt D, Moss, Newall R, Newman N, Rodgers, S, Thompson A. *Identifying Factors and Processes Contributing to Adjustment to Disfigurement*. The Healing Foundation, £495,000. 2005-2009

**G2. Sandy J (University of Bristol) (Gene Bank lead) & Rumsey N (Cohort Study lead)** *The Healing Foundation UK Cleft Collaboration: Cleft Gene Bank & Cohort Study*. The Healing Foundation, £4.79m, 2012-2017

### 4. Details of the impact

#### *The inclusion of psychologists in all UK cleft teams*

UWE research, highlighting the prevalence of psychological distress, the unmet psychosocial needs of patients and families affected by cleft and the ground-breaking finding that psychological factors played a significantly greater part in adjustment to cleft than aesthetic and functional outcomes, has played a leading role in ensuring that all patients with a cleft and their families in the UK have access to healthcare which includes a psychologist as a key and central member of the team.

Following a Clinical Studies Advisory Group (CSAG) enquiry into sub-optimal outcomes in cleft care in 1996, the Department of Health established a Cleft Implementation Group to oversee the reorganisation of cleft care. We submitted our research evidence demonstrating the importance of psychological factors in adjustment to a cleft to this Group. On the basis of this evidence, Rumsey was invited to join this expert group as the only psychologist. The deliberations were published in the form of a Government Circular (HSC98/238) and Department of Health reports (2002; 2003). All these publications included the recommendation that “an appropriately trained psychologist should be a core member of each cleft team”. Following a rolling programme of implementation (2003-June 2013), all UK cleft teams have now complied with this guidance. Psychologists across the UK now engage in screening, intervention, audit and research and have significantly altered the ethos and agenda of cleft care for all patients and families.

The results of UWE research have been used to improve the quality of the newly configured UK cleft psychology services. Furthermore, our research findings setting out the crucial importance of psychological care and including patient-centred outcomes in assessing the quality of care worldwide, has been taken up by The Global Task Force in Patient-Centred Outcomes in Cleft 2009-2017 and is being used in a programme of work to implement patient-centred outcomes as a

**Impact case study (REF3b)**

method of assessing the quality of care by cleft teams from the 70 member countries.

In the UK, with leadership from Rumsey, Bradbury (University of Manchester) and Middleton (Great Ormond Street Hospitals, London), the newly appointed clinical psychologists in cleft came together in 2004 to establish the Psychology Special Interest Group of the Craniofacial Society of Great Britain and Ireland (CFSGBI) to provide a professional 'home' for the new clinical psychologists in cleft. Our research identifying the need for psychological support and intervention influenced the Group's work from 2004-2009 to develop and adopt new UK Standards of Psychological Care in Cleft (2010). These now guide the clinical work of psychologists across the UK and provide the framework for UK-wide audit and research data collection [T1]. (We collate this audit and research data and are currently participating in projects to assess the impact of changes in care provision in the UK over the past 10 years.)

*Effective interventions for people with disfigurement*

The ground-breaking study of the largest sample of people with disfigurement to date led by Rumsey (2004-2009) (G1) resulted in the development of a theoretical framework of adjustment to disfigurement and to a stepped model to guide the development of interventions. This has resulted in the development of a range of evidence-based interventions suitable for patients with varying levels of psychosocial need, including two online interventions (one for adults [S1], with Bessell and Moss in 2009; one for young people [S2], with Williamson in 2011) which have demonstrated significant gains in psychological adjustment [T2]. These interventions are being used by in excess of 50 psychosocial specialists with their clients. (A study is currently underway, funded by NIHR Research for Patient Benefit, to assess their efficacy as self-administered interventions.) International interest is considerable and their use has been extended to professionals in the USA and Australia in 2013. Negotiations to translate the tools into the languages of 8 European countries are currently underway [T3].

*Evidence-based training and protocols for practitioners*

Rumsey's research has underpinned successful applications to fund international networks of practitioners and researchers. Rumsey and her team have developed evidence-based training materials and research protocols for practitioners and researchers from 25 European countries who are members of these networks. These materials are guiding vocational trainers, educators and social activists in 25 European countries in their work with people disadvantaged by appearance-related distress (including cleft). Rumsey also currently leads the Global Task Force on Holistic Outcomes in Cleft which includes representatives from 70 countries who are implementing methods of auditing psychological adjustment to cleft and its treatment, based on her research [S6].

*Supporting lay-led organisations in providing interventions and training materials*

Rumsey's research highlighting the prevalence of psychological distress, the need for psychosocial support, and the identification of key psychological factors contributing to adjustment in those affected by cleft and their families has resulted in long-term collaborations with the key lay-led organisations in the field: the charities *Changing Faces*, CLAPA (the UK's Cleft Lip and Palate Association), CleftPals (Australia), Facial Palsy UK [S4] and The Healing Foundation [S5; T2]. Over the past decade, this research, together with funded evaluations led by our team have contributed to shaping

- the content and focus of support and interventions offered by these charities (including written materials, online interventions, support offered face to face and over the telephone) [S3]
- the development of training materials for healthcare professionals (including a training package for cosmetic surgeons to facilitate psychological screening of potential patients) [T2].

*Public engagement*

We, together with others, have published a number of landmark publications, including most

**Impact case study (REF3b)**

recently The Oxford Handbook of Appearance (2012). The aim of such publications is to disseminate research findings to a broad audience of healthcare professionals, social scientists and policy makers. Rumsey is keenly committed to public engagement as a key mechanism of disseminating her research. She has engaged in public debate in over 50 contributions to national and local radio during the past 5 years (including Radio 4's *Today*, *Woman's Hour*; *You and Yours*, *All in the Mind*) as well as televised interviews and documentaries for BBC3 (*Jess: My New Face*), ITV's *Trinny and Suzannah* and Channel 4's *Beauty and the Beast*. More than 50 key note addresses have been given by Rumsey to audiences of healthcare professionals around the world since 2008. She has also engaged in audience debates at several Science Festivals in the UK and USA, public debates at The Science Museum, The Wellcome Centre and at The National Portrait Gallery and has led interactive workshops based on her research with large cohorts of GCSE and A level students at Disneyland Paris and London's O2. The team developed an interactive display for Bristol's public hands-on science exhibition @Bristol. This attracted 22,000 visitors in the first six months of 2013 and raised public awareness of cleft.

**5. Sources to corroborate the impact**

*Testimonials (available from UWE, Bristol).*

- T1. **Testimonial** from the Recent Past President of the Craniofacial Society of Great Britain and Ireland (CFSGBI)
- T2. **Testimonial** from the CEO of The Healing Foundation
- T3. **Testimonial** from Vice Rector of Godalen Vocational College, Norway

*Other sources*

- S1. [www.faceitonline.org.uk](http://www.faceitonline.org.uk) (website address for intervention for adults)
- S2. <http://www.yfaceit.co.uk> (web address for intervention for young people)
- S3. <https://www.changingfaces.org.uk/Resources-and-Guides> (Changing Faces self-help guides influenced by UWE research)
- S4. <http://www.facialpalsy.org.uk/about-us/who-we-are/medical-advisory-board/319>  
Corroboration that Rumsey is on the medical advisory board of Facial Palsy UK.
- S5. [www.thehealingfoundation.org](http://www.thehealingfoundation.org) (corroboration of Rumsey's involvement (as trustee) with The Healing Foundation)
- S6. [www.appearancetraining.com](http://www.appearancetraining.com) (training modules for vocational trainers and guidance counsellors developed by UWE team; UWE acknowledged in 'partners' section of site)