

Institution: Edge Hill University		
Unit of Assessment: A3 - Allied Health Professions, Dentistry, Nursing and Pharmacy		
Title of case study: Improving the healthcare experiences of children and young people.		
Period when the underpinning research was undertaken: 2013-2020		
Details of staff conducting the underpinning research from the submitting unit:		
Name(s): Lucy Bray	Role(s) (e.g. job title): Professor of Children's Health Literacy	Period(s) employed by submitting HEI: Seconded 2002-2013 Senior Research Fellow -2013-2018 Professor 2018 - present
Bernie Carter	Professor of Children's Nursing	15th February 2016 - present
Period when the claimed impact occurred: 2017-2020		
Is this case study continued from a case study submitted in 2014? N		
<p>1. Summary of the impact</p> <p>Our collaborative and co-produced research has had wide ranging impact on the care and management of acute and chronically ill children in clinical and community settings. Our impacts include: (1) informing the guidance and practice of clinical holding and restraint for children undergoing clinical procedures; (2) improving children's health literacy within hospital settings; (3) improving public understanding of the stigma experienced by young people relating to the disclosure of a chronic condition; and (4) enhancing the practice of assessment and management of pain in children with profound cognitive impairment. These impacts have been achieved through our innovative use of child-centred methodologies and the generation of highly accessed resources, guidelines and apps.</p>		
<p>2. Underpinning research</p> <p>More than 10 years of collaborative, child-centred research with children, families and health professionals both in the UK and overseas underpins this case study. Embedded throughout all stages of our research is an authentic commitment to engagement with children and families and much of our work has been co-produced with children, young people and families. Our work has contributed significantly to improving children and young people's healthcare experiences.</p> <p>Providing an evidence base to inform the practice of holding and restraint for children undergoing clinical procedures</p> <p>This work focussing on the use of holding (often against children's will) to carry out procedures is based on two primary research studies and a literature review. The research initiating this programme of work was a Grounded Theory study of the holding of children for procedures within a children's hospital (observation of 30 procedures and interviews with children, parents and health professionals). This study developed our conceptual understanding of holding as an inevitable and often unquestioned part of paediatric practice (output 1). This work then led to an international study (15 countries) conducted with colleagues from Australia and New Zealand to examine professionals' (n=827) reported practice when faced with an uncooperative child needing a procedure. We identified that professionals reported frequently being involved in situations where a child was held despite an awareness of what good practice 'looks like' when working with children undergoing procedures. The findings highlighted that professionals can struggle to step back from a difficult situation and balance the child's needs against the perceived need to get the procedure done (output 2). Our key recommendation from this body of work is the need for a 'clinical pause' prior to procedures to facilitate good procedural and child-centred care, to prevent an escalation of upset and the use of holding.</p> <p>Enhancing the conceptual understanding of children's procedural health literacy within hospital settings</p> <p>Health literacy is focussed on children's ability to access, understand and use health information to make meaningful choices and decision about their care. Our work is novel in contributing to this concept in relation to children undergoing procedures within hospital. An example of this work is the Xploro project (funded by Innovate UK), which used a two-stage design to investigate children's information needs when they attend hospital for a procedure. We conducted a mixed-methods before and after study (80 children, 80 parents) within a children's hospital (NW England) to evaluate the Xploro digital platform intervention. The findings showed that children who accessed Xploro reported statistically significant less procedural anxiety, more procedural</p>		

knowledge and were more involved in their procedure (important elements of procedural health literacy). The digital platform also had a positive influence on parents' procedural anxiety and knowledge (output 3). Our work contributing to a conceptual understanding of children's procedural health literacy is also demonstrated through our 'Children Coming to Hospital' project which involved facilitating drama workshops with 15 children to explore what supports and can act as a barrier for children when they attend hospital for procedures. The findings highlighted that children often felt 'small' and overshadowed during their procedure and that having/understanding their choices and being informed helped to positively influence their procedural experiences.

Enhancing conceptual understanding of the stigma experienced by young people relating to the disclosure of a chronic condition

The Being Me with IBD study has generated a portfolio of 4 papers. Funded by Crohn's and Colitis UK, it used a sequential, two phase, mixed methods design to explore friendships, well-being and feelings of social connectedness among young people (aged 14-25yrs) with IBD from three hospital settings, 2 in the NW England and one in London. Phase 1 (n=130) used a cross-sectional questionnaire design and addressed issues related to the association of disease symptoms with mental health and well-being, including loneliness, friendship quality and social self-efficacy (output 4). Phase 2 (n=31) used in-depth qualitative participatory interview methods to explore their friendships and friendship networks (output 5). Our novel findings show that specifics about the disease (severity and pain) predicted poorer mental health, suggesting that discussion of mental health should be part of the clinical dialogue between patient and consultant. In addition, embarrassment about their condition increased depression, anxiety and loneliness, which mediated the relationship between disease severity and well-being. Thus, it is important to consider how perceived stigma affects those with chronic illnesses, and this creates a driver for these issues to be explored in clinical practice (output 4). Another novel contribution arises from our findings around friendship; friendships can be supportive but also challenging. Clearer conversations within clinic settings (clinicians) and in education settings (teachers) could mitigate some of the challenges (e.g., disclosure) that young people face.

Enhancing the understanding and practice of the assessment and management of pain in children with profound cognitive impairment

Our work has focused on how parents and healthcare professionals (HCPs) acquire and develop the knowledge and skills to assess and manage pain in children with complex healthcare needs and who are profoundly cognitively impaired. It builds on a programme of work developed prior to 2014. The study used a convergent parallel mixed-method design using quantitative (phase 1: survey by parents) and qualitative (phase 2: interviews with parents and HCPs) data collection methods over an eight-week period. It focused on parent-reported pain experienced by children with profound cognitive impairment and parents' and HCPs' experiences and perceptions of assessing and managing pain in this diverse group of children. This work has provided key information about the frequency, nature and burden of pain for this group of children and advanced conceptual understanding of how parents, with very little formal training from HCPs, develop a robust 'sense of knowing' through embodied knowledge and via specifically situated experiential learning with their child (output 6). Our work also presents the concept of 'navigating uncertainty' as a theoretical explanation for the erosion of confidence often reported by HCPs who provide pain-related care for children with cognitive impairment. These findings reveal the tensions evident in communication between parents and HCPs and identified how these tensions could be mitigated through training and education, the importance of acknowledging parental expertise and the need to ensure that goals of treatment in terms of 'effective pain management' are shared by parents and HCPs (output 6).

3. References to the research

Output 1: Bray, L., Carter, B., Snodin, J., 2016. *Holding Children for Clinical Procedures: Perseverance in Spite of or Persevering to be Child-Centered*. Res. Nurs. Heal. 39, 30–41. <https://doi.org/10.1002/nur.21700>

Output 2: Bray, L., Ford, K., Dickinson, A., Water, T., Snodin, J., Carter, B., 2019. *A qualitative study of health professionals' views on the holding of children for clinical procedures: Constructing a balanced approach*. J. Child Heal. Care 23, 160–171. <https://doi.org/10.1177/1367493518785777>

Output 3: Bray, L., Sharpe, A., Gichuru, P., Fortune, P.M., Blake, L., Appleton, V., 2020. *The acceptability and impact of the Xploro digital therapeutic platform to inform and prepare children for planned procedures in a hospital: Before and after evaluation study*. J. Med. Internet Res. 22. <https://doi.org/10.2196/17367>

Output 4: Qualter, P., Rouncefield-Swales, A., Bray, L., Blake, L., Allen, S., Probert, C., Crook, K., Carter, B., 2020. *Depression, anxiety, and loneliness among adolescents and young adults with IBD in the UK: the role of disease severity, age of onset, and embarrassment of the condition*. Qual. Life Res. <https://doi.org/10.1007/s11136-020-02653-9>

Output 5: Carter, B., Rouncefield-Swales, A., Bray, L., Blake, L., Allen, S., Probert, C., Crook, K., Qualter, P., 2020. *"I Don't Like to Make a Big Thing out of It": A Qualitative Interview-Based Study Exploring Factors Affecting Whether Young People Tell or Do Not Tell Their Friends about Their IBD*. Int. J. Chronic Dis. 2020, 1–11. <https://doi.org/10.1155/2020/1059025>

Output 6: Carter, B., Arnott, J., Simons, J., Bray, L., 2017. *Developing a Sense of Knowing and Acquiring the Skills to Manage Pain in Children with Profound Cognitive Impairments: Mothers' Perspectives*. Pain Res. Manag. 2017. <https://doi.org/10.1155/2017/2514920>

All outputs are published in rigorously peer-reviewed journals of international standing and these papers are as a result of the award of rigorously peer-reviewed funding: Output 1 (Children's Research Fund Charity), Output 3 (Medical Research Council Biomedical Catalyst), Outputs 4 & 5 (Crohn's & Colitis UK), and Output 6 (WellChild).

4. Details of the impact

Our research, which has been co-produced with children and families (and voluntary agencies), has had a major impact on the lives of children and families receiving care within clinical and community settings. We claim four major areas of impact.

Informing the practice of clinical holding or restraint for children undergoing clinical procedures in hospital settings

Published in 2019, the Royal College of Nursing's national guidance for all nursing staff entitled 'Restrictive physical interventions and the clinical holding of children and young people' (source 1) directly refers to our research in relation to defining the boundaries of holding and restraint (pg5) (output 1), and the benefits of a 'pause' prior to commencing a clinical procedure ('*pause prior to a procedure to discuss and agree with a child and their parents/guardians what will happen during a procedure, what peoples' roles will be and if necessary what holding methods will be used, when they will be used and for how long (Bray et al 2018)*' pg6) (output 2). As a result of her publication track record, Professor Bray was invited to be a core member of the guideline writing group. This guidance is already informing clinical practice. Bray's research expertise was also called upon in 2019 to inform the development of training standards for the Restraint Reduction Network (RRN). The RRN training standards are mandatory in all NHS commissioned services for people with learning disabilities, autism, mental health conditions and dementia. Additionally, they are required to be adhered to for all services that are inspected by the Care Quality Commission. Bray was asked to support the development of these standards '*as a result of her published research into clinical holding and restraint*', in particular informing Standard 2.8 (source 2). To further ensure embedding of the research in practice we have run training sessions for health care organisations to raise awareness of the need to reduce the use of restrictive interventions and holding. Feedback from clinicians indicates a change in attitudes and practice, for example "*I am more honest now, and have a clearer idea of what is acceptable and what is not*" (source 3).

Improving children's procedural health literacy within hospital settings

Our research centred on children's health literacy has led to the development of a multi-media resource to support children entering healthcare and the development of a child-centred digital therapeutic platform (<https://www.edgehill.ac.uk/childrencomingtohospital>). 'Children Coming to Hospital' (CCH) is a multi-media resource including animations (for children and health professionals) and an information sheet which has been co-developed with children to improve their experiences when they attend hospital for procedures. The content of the resource was directly informed by our body of work on children's information needs and through working creatively with children during drama workshops (Bray et al 2019) and encourages children to have a voice and choice when they come to hospital. The CCH resource is now housed on 3 NHS hospital sites and is signposted on the websites of 4 key organisations. The resource has been freely available to download since its launch in February 2019 and was highly commended by the

British Medical Association Patient Information Awards (2019), endorsed by the Royal College of Nursing and selected as a case to demonstrate the real-world impact academic research can make as part of the 'Made at Uni' campaign (source 4).

An evaluation project using anonymous online questionnaires and interviews with children, parents and health professionals demonstrates that this resource '*makes a difference*' to professionals' awareness of how to improve children's experiences of having a procedure, parents' ability to support their child through a hospital visit and children's ability to ask "*why are you doing that?*" as evidenced in our annual activity report (source 5a). The project lead has presented this work at key events run by the Patient Information Forum which promotes the resource as helping reduce children's anxiety about coming to hospital (source 6) and the work "*is helping to inform the NICE Babies, Children and Young People Guideline recommendations that the NHS will be required to work towards when they are published in 2021*" (source 7). The recognition of our expertise in children's procedural information needs and preparation led to the award of Innovate UK research funding with an industry partner to inform the development of a child-centred digital therapeutic platform (DTx) (Xploro) <https://xploro.health/> for children coming to hospital (output 3). This platform uses ground-breaking technology (chatbot, avatar, augmented reality, 3D procedural) to prepare children for having procedures and our research informed the platform's rigorous development and evaluation. The DTx is used within the Royal Manchester Children's Hospital and the Christie Hospital in Manchester and is being translated into Spanish for Hospital Sant Joan de Déu. The work was highlighted as an example of good practice in the recently published national Patient Information Forum 'Guide to Producing Information for Children and Young People' (2020) (source 8), a leading publication for anyone developing information resources.

Enhancing conceptual understanding and reducing the stigma experienced by young people relating to the disclosure of a chronic condition

'Telling My Friends' is an evidence-based resource consisting of an animation and 3 information leaflets (<https://sites.edgehill.ac.uk/cc/>). It was inspired and based on the stories shared by the young people who participated in the Being Me with IBD study (outputs 4 & 5). This resource addresses the challenges and benefits of disclosing a diagnosis of IBD to friends. It was iteratively co-developed with young people from our advisory panel and through other PPI engagement with other people living with IBD to ensure that resource authentically reflects real life experiences, advice and solutions. Our approach means that the final resource is grounded in the reality of disclosing IBD to friends and colleagues in various settings (source 5b). Young people with IBD contributed to the voiceover for the animation. The resource is now being used in children's and adult hospitals and settings both in the UK and overseas (e.g. Royal Liverpool University Hospital, St Marks Hospital, London – a specialist bowel hospital), and within school nursing teams (e.g. in Sefton Borough). The animation is being shown in the virtual clinic waiting rooms on the NHS Attend Anywhere online clinic system. It has been adopted as a useful resource by Ampersand Health and an app that supports self-management for people living with IBD. The resource is being promoted by Crohn's & Colitis UK, the UK's leading IBD support charity (and the study findings have been used in its national campaign #ItTakesGuts "*to help inform our work around sharing mental health content with our audiences, to shine a light on the mental health impacts of the conditions*" (source 9). It further notes that the findings from the study feature as part of the Talking Toolkit on the "It Takes Guts" website <https://www.ittakesguts.org.uk/talk/talking-toolkit> and that "*this toolkit has had nearly 3,000 downloads and has been viewed by over 12,000 people since it was launched last year*" (source 9). It has also been translated into Portuguese and enthusiastically adopted by Crohn/ColitePT, a Portuguese patient advocacy charity as part of a suite of information and support brochures. This organisation launched the translated resource as the centre of a major campaign in August and September 2020 to coincide with children and young people returning to school, college and University. The President of CrohnColitePT (source 10) notes that feedback from parents and students with IBD shows that the resource is "*helping to raise understanding about IBD which is one of our key goals*". Within Portugal the resource has "*reach[ed] directly more than 3700 IBD patients/people with the information being further relayed to many more... and [via] monthly newsletter [to] more than 700 subscribers*" (source 10). We are in contact with colleagues in Brazil who plan to disseminate, post pandemic, via their network of IBD nurses.

Enhancing the understanding and practice of the assessment and management of pain in children with profound cognitive impairment

Our portfolio of research and key outputs on the assessment and management of children's pain extends back 20 years. Our more recent work, e.g., a mixed-methods study using interviews with clinicians and parents (output 6), has focused on children with profound cognitive impairment. Evidence from this study has contributed to the international evidence base as it addresses the challenges faced by both healthcare professionals and parents in assessing pain in this population. This work has underpinned the development of a new resource called 'Communicating Lily's Pain' <https://www.edgehill.ac.uk/communicatinglilyspain/>. The initial development of this resource arose from both the qualitative research evidence (output 6) and the opportunity of sustained engagement with parents, and collaborative working with a multi-disciplinary team including a theatre director, theatre producer, playwright/writer, and an illustrator/ animator. Through presentation of audio-visual soundscape performances in 5 venues, we have interactively engaged with the general public and illuminated understanding. 'Communicating Lily's Pain' is aimed at health professionals and parents with the intention of generating insights into experiences, promoting discussion and enhancing practice. Evidence of embedding change in practice comes from the use of the resource in practice (e.g. Bristol Royal Hospital for Children, Alder Hey Children's Hospital NHSFT) with feedback from staff attending pain management study days reflecting that their awareness and practice has changed, e.g. *"It's important to understand a patient may still be in pain – even if they can't communicate this...it's important to provide to same level of care"* (source 11). A Clinical Nurse Specialist commented *"Discussions arising from these resources have also prompted nursing staff on HDU to request that, in collaboration with the pain team, we trial the different pain assessment tools referred to in the HCP leaflet prior to introducing one of the tools onto the unit"* (source 11). Direct feedback from HCPs (n=>160) and parents via email, survey, in person, social media (source 5c) has demonstrated the importance of the resource, e.g. *"oh what a powerful video! It just hits the nail on the head that parents do know their children better than anyone else so our voices are extremely important, and we should feel valued in decision making"* (source 12). The Director of Communications and Engagement, WellChild notes that *"Based on our metrics the video and resource has been viewed more than 1,000 times on YouTube and more than 250 times from our site"* (source 12). The resource can also be accessed via other portals; estimated downloads or direct sharing of >800.

5. Sources to corroborate the impact

1. RCN. (2019) Restrictive physical interventions and the clinical holding of children and young people. Guidance for nursing staff. A clinical professional resource. RCN. London. <https://www.rcn.org.uk/professional-development/publications/pub-007746>
2. Testimonial, Director of Development at the Restraint Reduction Network
3. Feedback from health professionals on restraint reduction workshops
4. <https://madeatuni.org.uk/edge-hill-university/making-hospitals-less-frightening-children>
5. Research activity reports
 - a. Children Coming to Hospital Activity Report <https://www.edgehill.ac.uk/wp-content/uploads/The-CCtH-Activity-Report-v6.docx.pdf>
 - b. Being Me with IBD (Telling My Friends Resource) Activity Report 2019-2020. <https://www.edgehill.ac.uk/health/files/2021/02/Summary-Report-2019-2020-Telling-Friends-FINALv2-1.pdf>
 - c. Communicating Lily's Pain Activity Report 2019-2020 <https://www.edgehill.ac.uk/health/files/2021/02/TAGGED-Summary-Report-2019-2020-Communicating-Lilys-Pain-final.pdf>
6. Testimonial, Director, Patient Information Forum
7. Testimonial, Director of Nursing (Children) at Barts Health & the Clinical lead for Babies
8. Patient Information Forum (2020) Guide to Producing Information for Children and Young People. <https://pifonline.org.uk/download/file/509/>
9. Testimonial, Director of Services, Policy and Evidence, Crohn's & Colitis UK.
10. Testimonial, President, CrohnColitePT, Portugal
11. Testimonial, Clinical Nurse Specialist, Alder Hey Children's Hospital NHSFT
12. Testimonial, Director of Communications and Engagement, WellChild.