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Our patient publications are reviewed by our medical committee, ensuring the information they contain is pertinent and current, and we rely on those connections to help deliver our national conference for patients.

Our dedicated helplines are receiving more calls, emails and texts than ever, with a record 2730 enquiries in 2019.

As a patient-focused organisation, we regularly hear from our members about the challenges they face in receiving quality healthcare. We have collaborated on several projects to hear the patient voice (e.g. Cushing's disease and diabetes insipidus), with survey/questionnaire feedback results passed to the Society for Endocrinology and the NHS England Clinical

Reference Group for Specialised Endocrinology, to help inform and drive change where possible for patient benefit.

We highlight significant safety concerns, such as deaths from diabetes insipidus. We also have an annual campaign during the month of October to raise awareness of pituitary disease. These awareness months/campaigns are targeted at GPs/hospitals and the general public.

It is without doubt that this partnership between The Pituitary Foundation, as a patient group, and medical professionals has had a positive impact on the lives of many thousands of patients over the years. Collaborations and partnerships like this should be at the heart of all multi-disciplinary ways of working, to help ensure effective care delivery for patients.

**PAULINE WHITTINGHAM**

Endocrine Specialist Nurse, The Pituitary Foundation

*'The work done by The Pituitary Foundation would not be possible without our partnership with the Society for Endocrinology, senior endocrinologists, nurses and endocrine teams throughout the country.'*

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If you'd like to find out more about The Pituitary Foundation's services, please visit [www.pituitary.org.uk](http://www.pituitary.org.uk) or find us on Twitter @Pituitary\_org.

## COMMUNITY ENGAGEMENT AND PARTNERSHIPS IN MATERNITY SERVICES RESEARCH

WRITTEN BY MARY ADAMS AND COLLEAGUES

Engagement is not a one-way transmission of knowledge from experts to the public, and new programmes of work provide an opportunity for new beginnings. Partnerships imply the collaborative setting of priorities, as well as the dissemination of completed research to all partners. These partnerships are fostered with established or new communities over time. The different sorts of community and community interests have to be considered and accommodated, if engagement strategies are to be successful.

Recent innovations in community engagement in maternity services in England offer important lessons, and we look here at examples from our National Institute for Health Research (NIHR)-funded research. Maternity care is, inevitably, a matter of public interest, and the quality of care touches most families, often more than once. For over 50 years, some feminist and family interest groups have insisted that professional experts cannot ignore lay expertise and user experience.<sup>1</sup>

The NIHR has recommended patient and public involvement and engagement for over a decade<sup>2,3</sup> through their *National Standards for Public Involvement*.<sup>4</sup> New methodologies highlighting user experience are essential

tools from which researchers and services can learn ([www.invo.org.uk/resource-centre](http://www.invo.org.uk/resource-centre)). Acting on directives requires sensitivity to the histories and cultural concerns of different communities, and to how partnerships can be developed and sustained.

There are ethical questions to ask during the planning of partnership working, about how to manage hierarchies of power and status, how to build trust and mutual regard and, ultimately, whose views have legitimacy. This also includes questioning the language used about the people with whom we work. For example, we engage with women (not patients): women who find services hard to access (rather than women who are 'hard

to reach') and women living in areas of social disadvantage with social complexity (rather than 'vulnerable women').

### THE DISCERN PROJECT

The DISCERN Project<sup>5</sup> is examining how we can improve the disclosure and discussion of harm that has happened during maternity care with women and families. The project involves women and families throughout the project design and research cycle. This involvement ranges from agreement on the need for the research, through the co-design of the research objectives, data collection and analysis, to impact and dissemination activities.

Our community of service users comprises woman and families affected by serious incidents in NHS maternity care, and the charities and associations that support some of these 'experts by experience'. The families are engaged in study management, project advice and the interpretation of findings.

The partnership working with DISCERN is distinctive, in that it involves accommodating the many polarised views of service users on a very sensitive issue.<sup>6</sup> However, the importance of the topic to service users, as well as to clinical staff and managers, has been clear from the outset.

### PROJECT20

Project20 ([www.project20.uk](http://www.project20.uk)) is an NIHR-funded doctoral research project. It explores how specialist models of maternity affect the outcomes and experiences of women with social risk factors. The most disadvantaged in society, who are often the target population for specialist interventions, find it hardest to access and engage with services.<sup>7</sup>

To overcome this barrier, we relied on existing relationships that have been built between women and healthcare professionals. Discussions about the research were informal, flexible in location and time, and remunerated – being sensitive to the often-complex lives and limited finances of this group. Women's insights strengthened the ethics process and informed the recruitment strategy, data collection and analysis, to reveal findings that are useful to policymakers and those designing services.

### MATERNITY AND PERINATAL MENTAL HEALTH

NIHR Applied Research Collaboration (ARC) South London ([www.arc-sl.nihr.ac.uk](http://www.arc-sl.nihr.ac.uk)) is a research organisation that brings together researchers, health and social care practitioners and local people to improve health and social care in the area. In our NIHR-funded research programme on maternity and perinatal mental health, we are developing a positive working relationship with service users and local communities throughout the entire programme of work. We are considering how we can address poorer outcomes for women and babies living in areas of social disadvantage, as well as those from black, Asian and minority ethnic groups in south east London.

We are investigating the reasons for poorer outcomes for these women and families, and how changes in maternity and perinatal mental healthcare can help to address them. Recognising that maternal mental health is essential for the well-being of women, parental relationships and early infant development, one particular area of investigation concerns ways of improving the care and outcomes for women with mental illness.

We will involve women, communities and relevant organisations from the beginning of our work.<sup>8</sup> We have a dedicated, funded, service user researcher as the patient and public involvement and engagement lead (Mary Newburn). She advises and leads on building relationships between the researchers and community leaders, activists, maternity voices partnerships, charities and Healthwatch, amongst others.

Several processes and structures are being used to support the work, including online, flexible and informal, remunerated engagement events, which are advertised using social media to known contacts and networks, and held at times chosen to avoid when parents are most needed by their children.<sup>9</sup>

We have also developed Patient and Public Involvement and Engagement Strategy and Advisory Group meetings, which have been scheduled to take forward good working practices, to offer training and support for researchers and patient and public involvement and engagement partners, and to provide project advice to researchers. Communication is facilitated through social media accounts and email.

### IN CONCLUSION

We highlight the importance of partnership work, as well as the need for researchers and service improvement teams to take account of the expertise, time and development of the relationships required to establish and sustain this work. Interactions which aid crossing the boundaries between researchers and populations of interest are not always easy, but provide vital learning experiences. Furthermore, they facilitate research dissemination to the populations which it effects in creative and accessible ways.<sup>10</sup> Future plans include moving towards participatory research, and mentors in patient and public involvement and engagement for researchers.

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