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GROUP MEMBER INFORMATION

1. **Your name and school:** Professor Sally Kendall, Tamsyn Eida: Centre for Health Services Studies (CHSS), SSPSSR
2. **Personal research themes relating to SRT (brief synopsis and/or keywords)**

Maternal and child health; health and migration; immunisation; health inequalities.

Immunisation: Several European countries are currently facing outbreaks of vaccine-preventable diseases due to insufficient vaccination coverage rates. The WHO has recently declared vaccine misinformation as one of the main health threats for 2019, citing the need to develop primary healthcare, and address fragile and vulnerable settings and antimicrobial resistance. As in the UK, all EU countries have their own vaccination schedules recommending the vaccines to be given at various ages during childhood. However, many children remain unvaccinated across the block and its neighbours for a range of reasons including unequal access to vaccines and declining public confidence. This has led to the disruption or incompleteness of their vaccination schedules. In the UK, lower rates of vaccination are documented among children living in more deprived areas. For some vaccines, such as HPV, response and uptake rates are lower again among girls from ethnic minorities as well as girls from areas of greater deprivation.

For families who have migrated to the UK, understanding how the health service works in England and what vaccinations are given at different ages may be difficult to navigate and/or low on the agenda. Mechanisms to engage can be complicated and act as additional barriers, for example giving consent online for a child's school-based vaccinations. Partners in Kent and Medway school or Pharmacy have already described the multiple factors impacting awareness, understanding and uptake of services from individual factors and their immediate living and working conditions to the raft of structural barriers associated with the socio-political environment, government policies and the way services are designed and delivered, as well as the knowledge, skills, openness and flexibility within local services and teams. Cultural security is also an important factor. We have a working draft literature review presenting the documented factors affecting immunisation awareness, acceptability, uptake and completion – as well as the findings, discussions and recommendations of specific interventions to deliver improvements with migrant communities (though these interventions are all outside of the UK).

We are interested in particular in working with Kent's Roma communities on this issue. Recent research into the perceptions and experiences of Gypsy, Traveller and Roma with regards to childhood vaccinations, found positive levels of understanding of the benefits and acceptance within and across groups towards childhood and adult immunisations. Among the European Roma interviewed (from Slovakian and Romania), there were higher levels of acceptance of HPV vaccination than in the English Gypsy/Irish Traveller participants. However, the Roma participants noted the influence of adapting to life in a new country, new languages, low literacy and discrimination – and together, all of those interviewed made a series of recommendations orientated around establishing and valuing trust and continuity of care¹.

Returning to the WHO's statement on vaccination, it is clear that action on communication and information sharing is indeed necessary. There is a need across community and language groups for clear mechanisms, sharing meaningful information in appropriate and varied formats. These mechanisms must encompass context: how will these messages be prioritised, communicated and assessed at a health service level, particularly where services are stretched? Do the health service staff have sufficient training, time and support (eg: use of interpreters, flexibility to deliver outreach, cultural security and unconscious bias training) to engage migrant community members in two-way conversations about vaccination – or the partnerships to support the delivery of this work? In terms of improving mechanisms in primary care, recent local data suggests that there are approximately 600 children in Kent who are not registered with a GP. Therefore, as well as examining how primary care can better share information, encourage uptake and deliver vaccinations, we must address the barriers and enablers to getting registered and using primary care. Trust remains central, particularly in view of the fact that a sizeable portion of Roma community members are living in relatively fragile settings influenced by the current political climate, income instability, discrimination and inconsistent access to information and services. Roma people need to be part of the ongoing work, voicing their experience, concerns and recommendations, and explaining the wider contextual factors which influence the work

¹ Jackson, C., Bedford, H., Cheater, F.M. et al. (2017) *Needles, Jabs and Jags*: a qualitative exploration of barriers and facilitators to child and adult immunisation uptake among Gypsies, Travellers and Roma. BMC Public Health 17: 254
<https://bmcpublichealth.biomedcentral.com/track/pdf/10.1186/s12889-017-4178-y>

of services and local people. We are currently working with two projects in Kent: Kent Community Health Foundation Trust's Healthy Communities project and Red Zebra's Roma in the Lead project. Both are working to improve understanding, trust, connectivity and use of services through a combination of outreach, tailoring and targeted work at community and service levels. We are keen to document the learning that these projects are bringing through our existing evaluation of their work and extend the focus on immunisations specifically.

3. Current and possible international/national partnerships (mark as 'existing' or 'possible')

Existing

- Sally Kendall is the chair of the *European Forum for Primary Care*, an internationally recognized organisation with partnerships with the recent Global Vaccination Summit (WHO). SK is on the European Steering Group for Influenza Vaccination.
- Internationally, Sally is also an Adjunct Professor at the *Ngangk Yira Aboriginal Research Centre, Murdoch University, Western Australia* where she works on maternal and child health, with a particular interest in cultural security (recent paper on Cultural Security in the Perinatal Period for Indigenous Women in Urban Areas: A Scoping Review). She is also the PI on a GCRF partnership grant working with colleagues in Ukraine on maternal and infant health that includes immunisation.
- extensive expert partners in primary and community healthcare research, representation and delivery, such as:
 - the Institute of Health Visiting
 - Professor Helen Bedford at University College London's Great Ormond Street Institute of Child Health, co-author of recent research on the barriers and facilitators to acceptability and uptake of immunisations with Gypsy, Traveller and Roma (Slovak and Romanian) groups and explore their ideas for improving immunisation uptake
 - Kent Community Foundation Health Trust
 - Red Zebra Roma in the Lead programmes
 - Kent and Medway Local Authorities public health departments
 - Public Health England

Possible

- NHS England
- Faculty of Public Health

4. Proposal[s] for Specialist Workshops. (NB: specialist workshops are problem-solving workshops where invited experts will work with a team of Kent researchers on a specific problem, often in collaboration with non-academic partners. These are likely to be specific to one discipline or a few related disciplines)

- **specific issue: understanding perceptions, barriers and enablers in childhood immunisation communication and delivery processes; identifying gaps and improving mechanisms within the immunisation process**
- **proposed workshop: to include**
 - local multi-sectoral partners, such as:
 - Immunisation Team; Healthy Communities project (Kent Community Health Foundation Trust);
 - Kent and Medway Immunisation and Screening Team (NHS England);
 - primary care partners through Kent and Medway CCGs;
 - Unaccompanied Asylum Seeking Children's team (eg: Kent County Council; NHS England; KCHFT);
 - CVS partners: Red Zebra Roma in the Lead and Integrated Communities projects, KRAN (working with unaccompanied asylum seeking children) among others.
 - academic partners, such as Helen Bedford
 - national sector representatives partners, such as the Institute of Health Visiting, Faculty of Public Health and Public Health England

5. Proposal[s] for Interdisciplinary Thematic Workshops (to link researchers across Sciences-Humanities-Social Sciences)

Cumulative impact of Brexit, the hostile environment and austerity on perceptions of, engagement with and uptake of services among diverse migrant communities. While public health programmes increasingly advocate whole system approaches, and government funds are directed at integration and efficient use of services, to what extent can real change be made in this context? What are the opportunities for improvement here and how can they be delivered?

6. Ideas for public engagement, impact and 'outputs'

Collaboration with partners with existing links with diverse communities in Kent, eg: the Red Zebra Roma in the Lead and Integrated Communities projects, and KCHFT's Healthy Communities project, among others.

Commitment to funding and delivering the co-development of project plans with real representation from migrant community members. Support to develop community members who are interested in becoming peer researchers, and opportunities to build experience. This builds on the CHSS commitment to public engagement in all areas of research.

7. Blue Skies: My vision for a group like this...

In early consultation work with Roma community members (across Kent) for the Roma in the Lead project, focus group participants emphasised their desire to be proactive, be listened to and to be in a position to frame the questions and debate. More opportunities to researching collaboratively, with people with a migrant background who are living in Kent included from the outset and throughout – and the appropriate support and mentorship to deliver this.

Improving research into practice. This is especially relevant around commissioning of health services, influenced by the lack of clear data for migrant health and inconsistencies in the ways that migrant health needs are sought or considered in Joint Strategic Needs Analyses.

8. List of external partners, past, current and future, HEI and non-HEI and brief details of existing/projected relationships/projects.

- Local partners/details: Evaluation of KCHFT project which focuses on migrant communities who have settled in Kent, living predominantly in Dover, Folkestone and Margate and Gravesend. The aim is to reduce barriers and increase access to health services by local migrant families to address inequalities and encourage take-up of preventive services. Evidence shows particularly low engagement by Roma communities with family planning, dental care and general practice. KCHFT will employ and train staff largely from the Roma community as community based health advisers. The evaluation will be supported by 'Roma in the Lead', a project managed by Red Zebra which is working closely with Roma families to build trusting relationships. The CHSS research team will use realist evaluation and social justice frameworks. Start date: 07/01/19 End date: 31/10/20
- Also working with the Kent Roma Interest Group (KRIG), a group of local statutory and community partners working to connect, learn from and develop work by and with the Roma community in Kent and Medway; and the South East Strategic Migration Partnership (SESMP)² who, working with statutory and non-statutory partners across Kent and beyond, provide a leadership, co-ordination and advisory function for migration in the South East.
- National: Institute of health visiting
- International: Sally is co-chair of the International Collaboration of Community Health Nursing Research, a UK charity supporting international community nursing research dissemination (www.icchnr.org). Also, Associate Investigator on a major NHMRC project in Australia concerned with the early parenting experiences of Aboriginal parents, she is also the PI on a GCRF partnership grant working with colleagues in Ukraine on maternal and infant health that includes immunisation.

² <http://www.secouncils.gov.uk/about-us/about-sespm/>

9. List of all relevant papers and monographs (including in press and forthcoming). It is important that all participating disciplines are represented.

Marriott, R., Strobel, N., Kendall, S., Bowen, A., Eades, A., Landes, J., Adams, C. and Reibel, T. (2019). Cultural Security in the Perinatal Period for Indigenous Women in Urban Areas: A Scoping Review. *Women and Birth* [Online] **32**:412-426. Available at: <http://dx.doi.org/10.1016/j.wombi.2019.06.012>.

Howe, A., Mathie, E., Munday, D., Cowe, M., Goodman, C., Keenan, J., Kendall, S., Poland, F., Staniszewska, S. and Wilson, P. (2017). Learning to work together - lessons from a reflective analysis of a research project on public involvement. *Research Involvement and Engagement* [Online] **3**:1-12. Available at: <http://dx.doi.org/10.1186/s40900-016-0051-x>.

10. Ideas for New Practices in Education that could be developed in relation to the theme

In terms of health provider education, improved understanding of both the experience of migration and impact of the design of services in the UK for the understanding and accessibility.

11. Ideas for subthemes that link disciplines

- Health
- Trust, security and how migration and migrants are framed
- Culture and experience

12. List of funders that we could apply to (innovation and enterprise as well as grant awarding bodies)

- NIHR (especially the Research for Patient Benefit stream)
- Wellcome Trust (Social Sciences stream)
- GCRF
- ESRC
- AHRC
- EU H2020 or equivalent, Marie Curie Fellowship

13. Ideas for innovative practice in public engagement

Not sure if this is innovative, but greater levels of collaboration that redresses the power dynamic. PPI groups run as outreach and on rotation. Work with migrant community members may require budgeting for interpreters and translators. Training for researchers in how to engage, understanding the potential for working through interpreters and using translated material and how to work with interpreters. Considering the cultural structure of research projects and being open to change. Including migrant community members in this process and any training. Consider research practices from other cultures to 'decolonise' research from a western perspective.

14. General comments: