

JOINT PROGRAMME FOR PATIENT, CARER AND PUBLIC INVOLVEMENT IN COVID RECOVERY: UPDATE REPORT (MAY 2021)¹

1 Introduction

- 1.1 Following the successful development of a proposal for a *Joint Programme for Patient, Carer and Public Involvement in Covid Recovery*, in September 2020 Guy's and St Thomas' Charity, supported by King's College Hospital Charity, agreed to fund a two-year programme to support the involvement of patients, carers and the public in the ongoing change and development of services necessitated by the Covid pandemic.
- 1.2 The purpose of this paper is to:-
- i. Provide a brief introduction to the programme, its aims and research partner
 - ii. Briefly describe the governance arrangements for the programme, including the Steering Group and the partners involved in the programme
 - iii. Highlight the programme's work to date, which includes:-
 - a) The completion of scoping interviews with clinical leaders and external partners, which were used to inform a prioritisation exercise and shape the direction of the programme
 - b) A prioritisation exercise undertaken by the Steering Group, which resulted in the identification of themes and topics to be developed into project briefs
 - c) Four workshops with clinicians, operational staff and Steering Group members to shape the development of project briefs
 - d) The design and fieldwork for a survey that is exploring patient and carer attitudes and behaviours in response to the Covid pandemic, and how its findings will be used.

2 About the programme's development, its aims and its research partner

- 2.1 The proposal for the Joint Programme was developed in collaboration with patient and public engagement leads across Guy's and St Thomas' NHS Foundation Trust (GSTT), Royal Brompton and Harefield Clinical Group (RBH) and King's College Hospital NHS Foundation Trust (KCH). Ongoing service delivery and rapid changes to models of care, including the urgent integration and transformation of services necessitated by COVID-19, means that patient care and services for our local populations and beyond, continue to be significantly affected. Importantly, the programme will support each partners' commitment to patient participation, with its primary aim being to work with patients, carers and the public to understand:
- shifts in public attitudes and behaviours toward accessing care in different parts of the healthcare system and the risk that patients and the public may retract from accessing the care they need now or in the future

¹ This report is based upon a paper that was first presented to Guy's and St Thomas' Strategy and Partnerships Executive Committee on 25 February 2021.

- how the changes we are making or have made continue to affect patients, their families and carers experiences' of accessing care, using new or rapidly changing models of care
- variations in experience of care between different protected characteristics
- how we can improve and further develop services.

2.2 Before standing up the programme and its Steering Group, the founding partners identified Ipsos MORI as the preferred research partner, due to their knowledge of the trusts and their extensive body of opinion research in healthcare service design and delivery. They are committed to working in collaboration with the programme, as well as with creative engagement specialists to support the wide range of people, including parts of our patient populations who are seldom heard.

3 The programme's partners, its Steering Group and governance arrangements

3.1 The programme's senior responsible officer (SRO) and Steering Group Chair is Jackie Parrott (Chief Strategy Officer, GSTT). To ensure the support of Executive Directors and the participation of clinical leadership, together the Chief Nursing Officers and Medical Directors of each partner trust nominated clinical leads to support the programme through what is now a very active and engaged Steering Group. It involves partners from South East London Clinical Commissioning Group, our trusts' charities (GST Charity, KCH Charity, RBHH Charity), along with patient-public stakeholders, including governors and Healthwatch bodies. It is hosted by the GSTT Patient and Public Engagement Team, led by Andrea Carney (Head of Patient and Public Engagement) and supported by Philippa Yeeles (Patient and Public Engagement Specialist).

3.2 Together, all partners including patient-public stakeholders, are actively involved in driving the direction and development of the programme via the Steering Group, a 22-strong group which has seen excellent attendance since its inception. Where the programme or Steering Group requires the advice of Executive Directors, the SRO will brief and seek the views of partners via their preferred committees. Where committee schedules do not allow and to avoid delays to programme work, the SRO will refer directly to individual Executive Directors, as appropriate.

3.3 Bi-annual reports will be prepared by the GSTT Patient and Public Engagement Team on behalf of the partners and each partner trust will be responsible for sharing the same report with the above committees. Copies of the reports will also be shared with the Steering Group. NHS partners are responsible for identifying a committee to which the programme will report bi-annually.

4 Defining the programme's areas of focus: scoping interviews and the Steering Group's prioritisation exercise

4.1 The early proposals for the programme purposely included a broad potential scope to allow partners, including patient-public stakeholders, the opportunity to shape the programme. Between October 2020 and January 2021, Ipsos MORI was commissioned to design and facilitate a series of in-depth discussions² with key stakeholders from across each of the partners. They explored a range of issues including immediate and longer-term priorities for service delivery, and what issues, services or patient groups should be taken into account when designing the programme. In total, 21 individuals took part in the discussions from the following groups (Ipsos MORI, 2021):

- Nursing, Paediatrics, and Allied Health Professional leads and clinical directors from GSTT, KCH and RBH
- GSTT, KCH and RBH charities
- South East London Clinical Commissioning Group / Integrated Care System
- Healthwatch Lambeth and Healthwatch Bromley³

Informed by the findings of the above, the knowledge and views of its members, the Steering Group completed a prioritisation exercise in its meeting of 27 January 2021.

4.2 A copy of the full report of the scoping interviews is available on request. The findings highlighted the following recurrent themes:-

- Considerable changes to outpatient and elective care (i.e. postponed or cancelled appointments, consultations or the management of conditions moving to virtual communications).
- Shift to virtual and remote access care and the implications this might have on patients who might have difficulty accessing this means of care.
- Identifying vulnerable and seldom heard groups and responding to their specific needs.

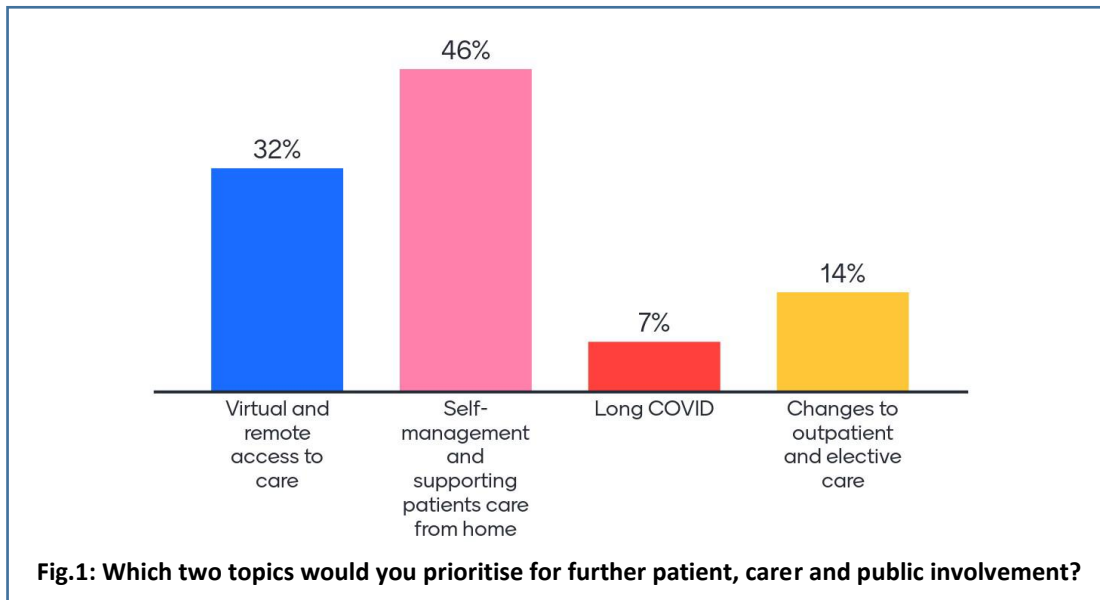
4.3 The Steering Group considered the findings of the interviews at its meeting on 27 January. Members participated in two sessions of four breakout groups, as well as a polling exercise, to identify and prioritise the topics and themes noted below:-

- Virtual and remote access to care
- Changes to outpatient and elective care (including delayed/paused treatment)
- Self-management and supporting patients' care from home
- Long COVID.

² The interviews were carried out between October and December 2020. At the time, the NHS was moving out of Phase 3 of its COVID-19 response, and returned to the highest level of emergency preparedness in early November (the UK went into a second lockdown during this time) (Ipsos MORI, 2021).

³ Healthwatch Southwark were unable to participate and that Healthwatch Bromley on account of this being one of the key Healthwatch bodies that KCH engages with.

4.4 Group members were asked to select their top two priorities from the list of four to give a sense of weighting between the different areas (see Figure 1 below). The four topics were then considered further in discussion groups. Each group was assigned a single topic, in order to begin to shape the approach.



4.5 At the end of March, each topic was the subject of a workshop that brought together members of the Steering Group with trust colleagues working in these areas, to develop the topics into a series of draft project briefs. A total of 66 people attended the four sessions. The workshops provided rich knowledge, insights and ideas that were thematically analysed. The analysis directly informed the development of a draft tender document that includes three project briefs on the following topics:

- **Virtual access to care**
- **Waiting for treatment and self-management**
- **Long COVID**

4.6 In May, the draft tender document was reviewed by the Steering Group alongside further feedback from trust colleagues who had participated in the workshops. Final revisions to the tender document are being made before the procurement process to identify delivery partners is undertaken. The programme envisages that the three projects will commence in September.

5 About the patient and carer Covid attitudes and behaviours survey, how its findings will be used and how stakeholders have informed its design

- 5.1 In May, the programme marked the start of its patient-public facing work with a 13-minute, Ipsos MORI telephone survey (sample size = 1,500). The survey aims to understand changes to patient, carer and public attitudes and behaviours in relation to accessing care and services over time – this includes both adult and children’s services. It will capture information about the behaviours and attitudes of our populations to meaningfully inform how services continue to be designed, improved and delivered during COVID-19 second wave, recovery and beyond. Its design has been led by Ipsos MORI in close collaboration with the Steering Group and a survey design sub-group.
- 5.2 Importantly, we will also explore attitudes and behaviours by different equalities characteristics (gender, age, ethnicity, disability / presence of long term conditions). The eligible population of patients, carers and the public for GSTT, KCH and RBH is large and diverse, and as such, all partners (via the Steering Group), together with Ipsos MORI, have given careful consideration to the sample design, and content of the survey, which will explore:-
- a) General feelings about the virus and perceived levels of risk
 - b) Experience of accessing existing care for current needs (questions for current service users/ those with regular care needs)
 - Use of services for existing care needs (e.g. GP, community services (incl. home visits) outpatients, elective care, urgent and emergency care
 - c) Accessing care and services for new or future needs - including community, outpatient, elective, urgent and emergency.
 - d) Adapting to service changes driven by the pandemic, over the short, medium to long-term (e.g. virtual appointments)
- 5.3 Fieldwork was completed by the end of May. A draft report of the survey findings will be presented to, and reviewed by, the Steering Group at the start of July. The final report will be shared widely through the trusts’ and Steering Group members’ networks to ensure that the findings are made fully accessible to services, programmes and projects involved in COVID recovery.

6 Further information

- 6.1 Should you want any further information about the Joint Programme, in the first instance please contact:
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