



Thames Valley and Surrey Care Records Partnership Programme Board paper

Meeting Name:	Thames Valley and Surrey Care Records Programme Board
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Date of Meeting: 26.11.19	Paper No: 05
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Title of Paper: Ethics and Engagement Advisory Board First Recommendations

Paper is for:	Discussion		Decision	✓	Information	
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<p>Purpose and Executive Summary: The first meeting of the Ethics and Engagement Advisory Board was held this month. It considered papers on the TVS Lead Controller model and Data Subject Rights Policy & Process (discussed at the last Programme Board). It also considered local Fair Processing Notices on the TVS Partnership website. This paper makes recommendations for the Board to consider based on the discussion at the Advisory Board.</p>

<p>Engagement: clinical, stakeholder and public/patient: All</p>
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<p>Financial Implications of Paper: There are resource implications for the work suggested in the recommendations.</p>
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<p>Action Required: 1: Endorse the Terms of Reference for the Ethics and Engagement Board. 2: Discuss and agree actions against recommendations made. 3: Agree that data access controls should be considered at the next Ethics and Engagement Advisory Board in January.</p>
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<p>Date of paper: November 22nd 2019</p>

Conflicts of Interest	
No conflict identified	X
Conflict noted: conflicted party can participate in discussion and decision	
Conflict noted, conflicted party can participate in discussion but not decision	
Conflict noted, conflicted party can remain but not participate in discussion	
Conflicted party is excluded from discussion	



Ethics and Engagement Advisory Board First Recommendations

Introduction

Digital approaches to health and care underpin current NHS policy and are seen as essential to ensuring care is sustainable in the future. When, and how, we use individuals' health data is central to digitally enabled care: for individuals, for groups of patients and for the general population.

This field of digital innovation is, and will continue to be, fast moving with new and ongoing debates around, for example:

- how views on using patient data may change over time, be different for different settings or be different for different data items;
- the burgeoning number of apps and devices and their interface with the resulting need for statutory data storage and use;
- secondary uses of patient data for both planning health and care and for research.

These debates will be won or lost depending on the degree to which they can be held in a timely, transparent and meaningful way for the public and the full range of patients and professionals. With this in mind, the Thames Valley and Surrey (TVS) Care Records Partnership committed to establishing an Ethics and Engagement Advisory Board, the first meeting of which was held on November 13th 2019.

Purpose

The purpose of the Ethics and Engagement Advisory Board is to support the work of the TVS Care Records Partnership by (see also draft Terms of Reference at appendix 1):

- Providing advice to the TVS Partnership Senior Responsible Officer (SRO) and Programme Board on ethical issues that should be considered and addressed in the TVS Care Records Partnership work programme.
- Providing advice to the TVS Partnership SRO and Programme Board that will support transparency for the purpose and process in relation to using patient data, so that public trust is built and maintained.
- Acting as a forum for discussion across the TVS Partnership to support coordination of action in involvement and engagement with patients and the public, clinicians and practitioners.
- Supporting and sharing best approaches to involvement and coproduction with patients and the public, clinicians and practitioners.
- Promoting best communication methods, including consideration of the voice and needs of seldom-heard communities.
- Advising on approaches to secondary use of data such as access to data – who, what and when.



Meeting 1 Agenda

The Ethics and Engagement Advisory Board was asked to consider and discuss:

- TVS LHCR – Lead controller model: discussion paper, v1 Oct 2019
- TVS Care Records – Data Subject rights policy & processes: discussion paper, v1. Oct 2019 (Related papers are under Item 4 for this Programme Board, Information Governance)
- Local Privacy Notices

Recommendations

The Ethics and Engagement Advisory Board recommends that the Programme Board consider how to:

1: Ensure language used in all papers is easily understood by the full range of people who might be interested, including members of the public. It is recognised that many papers are technical in nature, however the rules of [Plain English](#) can be followed, as can guidance from [Understanding Patient Data](#) (these principles have been previously endorsed by the Programme Board). In addition, always considering infographics as well as text, for example to show how the Lead Controller model will work. Finally, making greater use of the TVS Communications Coproduction Panel would also be of benefit.

2: Develop a clear, public-facing guidance statement of how individuals can see what data is both held, and shared by any, and all, health or care organisation. This should include a form of words that an individual could use with any individual organisation that would allow them to access all their health and care data held and shared, rather than having to ask many organisations the same, or a similar question. In the longer term, developing a more centralised 'one stop shop' process should be considered.

3: Similarly, develop a clear public-facing description of what personal data sharing and usage individuals can object to and opt out of and how to do this. The use of infographics and decision trees could be considered for both of these descriptions.

3: Assure that the Lead Controllers appointed are appropriately qualified and connected to their local health system in order that they can truly represent their communities, for example by developing a role description.

4: Ensure transparency in the work of the TVS Programme through communication to staff and the public about the data included in each release, who can see that data and for what purpose. Similarly, for existing and new use cases.

5: Communicate the benefits of using patient data from both the point of view of staff and of patients. It may be helpful to use existing resources such as [Sam's Story](#) or [Understanding Patient Data](#) animations and case studies.



6: Ensure that local Fair Processing Notices, linked from the TVS Partnership website are in plain English and have common content. Similarly, ensure that the notices are easy to access; currently they are not easy to find and only one of the four buttons available to click through to a local notice does so.

Action required

- 1: Endorse the Terms of Reference for the Ethics and Engagement Board at appendix 1.
- 2: Discuss and agree actions against recommendations made.
- 3: Agree that the Ethics and Engagement Advisory Board consider the ethics and engagement issues raised by data access controls at the Advisory Boards' next meeting in January.



Appendix 1



Thames Valley & Surrey (TVS) Care Records Partnership

Ethics and Engagement Advisory Board

Terms of Reference v 2

1. Introduction

Digital approaches to health and care underpin current NHS policy and are seen as essential to ensuring care is sustainable in the future. When, and how, we use individuals' health data is central to digitally enabled care: for individuals, for groups of patients and for the general population.

This field is, and will continue to be, fast moving with new and ongoing debates around, for example:

- how views on using patient data may change over time, be different for different settings or be different for different data items;
- the burgeoning of apps and devices and their interface with statutory data storage and use;
- secondary uses of patient data for both planning health and care and for research.

These debates will be won or lost depending on the degree to which they can be held in a transparent and meaningful way for the public and the full range of patients and professionals.

2. Purpose

The Ethics and Engagement Advisory Group will support the work of the Thames Valley and Surrey (TVS) Care Records Partnership by:

- Providing advice to the TVS Partnership SRO and Programme Board on ethical issues that should be considered and addressed in the TVS Care Records Partnership work programme.
- Providing advice to the TVS Partnership SRO and Programme Board that will support transparency for the purpose and process in relation to using patient data, so that public trust is maintained.
- Acting as a forum for discussion across the TVS Partnership to support coordination of action in involvement and engagement.
- Supporting and sharing best approaches to involvement and coproduction with patients and the public, clinicians and practitioners.
- Promoting best communication methods, including consideration of the voice and needs of seldom-heard communities.
- Advising on approaches to secondary use of data such as access to data – who, what and when.



3. Membership

- The membership will be drawn from across the TVS Care Records Partnership systems and comprise 50% of members representing the population and 50% of members representing staff and professional groups including: social care, primary and secondary care clinicians, junior staff, research, ethics, allied health professionals, information governance, Healthwatch and seldom heard groups of the population.
- The TVS Partnership SRO will have observer status at Advisory Group meetings.

Advice to the Ethics and Engagement Advisory Board

- Other staff from the TVS Care Records Partnership will be invited to Advisory Board meetings as needed, in order to provide information to support discussions at the Advisory Board.

4. Chairing

- The Advisory Board will have a professional and lay co-chair, supported by the TVS Care Records Partnership Coproduction Lead.
- The Co-chairs of the Advisory Board will be members of the Programme Board.

5. Secretariat

- Will be provided by the TVS Partnership Core Team.

6. Relationship with TVS Care Records Programme Board

- The Advisory Board will provide advice to, and Board papers for, the Programme Board after each meeting.
- The TVS Care Records Partnership Coproduction Lead, as a member of the TVS Programme Board, is responsible for providing Programme Board papers and other outputs from the Advisory Board.
- The Programme Board and Programme SRO can request that the Advisory Board consider particular papers, questions or activities.

7. Responsibilities of members

- Members are asked to contribute their thoughts and expertise as independent members of health and care staff or the public.
- Members are not asked to represent any particular organisational or geographical constituency.

8. Frequency

- Will be determined by the need for advice, there will be no more than three meetings a year, with some virtual work between meetings.