Consultation by the Professional Record Standards Body (PRSB) on a core information standard for local health and care records

Response from the Faculty of Public Health

April 2019

A. Introduction

The **Faculty of Public Health (FPH)** is a registered charity and a joint faculty of the three Royal Colleges of Physicians of the United Kingdom (London, Edinburgh and Glasgow), with more than 4,000 members. Its aims are to promote for the public benefit the advancement of knowledge in the field of public health; to develop public health with a view to maintaining the highest possible standards of professional competence and practice; and to act as an authoritative body for the purpose of consultation and advocacy in matters of educational or public interest concerning public health.

This submission has been prepared in collaboration with the **Health Statistics User Group (HSUG)**.

We welcome this opportunity to comment on the proposals for a local health and care record. The Faculty is pleased to be associated with the work of PRSB and offer advice in this important area. We would encourage the PRSB team to engage in future consultations in a more conventional way than through a web-only presentation, and to ensure their activity is visibly joined up with other groups working in the field of health information and data standards.

The proposed record is a valuable initiative to improve the coordination of care for individuals across organisations and care sectors. It has the potential to increase sharing of useful information, speed up the delivery of care and prevent errors and omissions caused by missing or incomplete data. If fully developed along the lines intended, it could also help to inform and empower individuals about their own health and care.

In this submission, we focus mainly on those issues of greatest importance to improving the health of the population as a whole, including points relevant to understanding of the wider determinants of health, reducing health inequalities, and facilitating research.

B. General issues

Integrated care

We welcome the concept of a core data standard which will facilitate information sharing to support joined-up care. A well-integrated health and social care service offers the greatest benefit for the individual patient and the health of the population, as well as being beneficial for cost-effectiveness across the care sector as a whole. The principle of 'joining up' should not be limited to NHS primary, community and secondary (or tertiary) care services, but needs to be understood as including all aspects of care provision and promotion of wellbeing.

Thus, to make sure the maximum benefit is gained from this opportunity to improve integrated, person-centred care, the following general points should be taken into account:

- The aim of full inclusion of social care information should be made clear, as this is an essential aspect of integrated care. In addition, social care data is not well standardised or shared nationally, so the initiative could contribute to improvement in that direction. The wording of the documents should be clearly inclusive, e.g. it should read 'health and social care' rather than just 'health and care' throughout.
- Specific reference should be made to linkage with relevant local authority-held records or inclusion of extracts from them, defined broadly to include e.g. any register of homeless persons, persons at risk, recipients of funding for adaptations, as well as adult and child social care services.
- It would also be helpful to refer to the inclusion of information on contacts with voluntary sector care providers and sharing of the record with them where appropriate.
- Services for prevention and health promotion, whether operating at individual or community level, have an essential contribution to make to integrated care. Information about health determinants and lifestyle issues should be specifically included, and focussed on identifying both risk factors and opportunities for intervention and support.

Integrated information systems

Opportunities should be sought to clarify and communicate the purpose of the core information, and to articulate the relationship between the core information set and existing information systems and standards. As far as possible, the definition of the core information should match existing record structures and standards which exist for specific purposes. The aim should of course be for the core information set to be populated primarily from operational data, acting as an integrating structure across the data held by different services and avoiding creating a new 'data silo'.

The development of record content cannot be an isolated activity, as the information to be gathered should be based on the range of operational needs involved. The potential for secondary uses of the data also has to be taken into account throughout.

Data for public health

We consider it a priority from the perspective of understanding local public health issues and enabling effective preventive interventions to include meaningful information on social factors, unmet care needs, barriers to care provision, and links to the individual's context such as family, locality and wider community. The content should be informed by public health and epidemiological concepts as well as the need to record clinical data.

Sufficient attention is needed to ensuring that the record will be useful for research and public health intelligence at an aggregate level, in addition to the benefits for direct patient care. A well-structured and comprehensive core information standard needs to be recognised as a resource for public health monitoring and research which could be of huge public benefit when analysed in aggregate form, subject to the proper safeguards for confidentiality and data protection.

For this reason, as well as to ensure interoperability of systems and adherence with NHS national data standards, compliance with recognised classifications, nomenclatures and statistical coding frames will be essential for all parts of the record.

Patient involvement

The inclusion of patient-generated information such as the 'About me' section is welcome. However, there is a risk that such a section could be little-used and seen as tokenistic. Further thought would be very useful on how the individual's own perspective can be integrated more widely into the data collected, and not limited to a single area of the record.

While the consultation is on content and not process, more thought could probably be given to issues of patient access, such as how both patient and professional preferences on confidentiality around subjects of varying sensitivity can be clearly indicated.

Ethics and confidentiality

The wide-ranging scope of the core information set raises difficult issues around ethics and confidentiality, beyond those routinely faced in the handling of patient data. In particular:

- The information set includes categories of information which are particularly sensitive, e.g. ethnic origin and a person's sex life or sexual orientation. These subjects require particular care according to the data protection legislation.[1]
- The information set contains information about other individuals, such as family members and other contacts. Unlike the index patient, these individuals may not have given consent to information about them being recorded or shared.
- The shared nature of the information set means that information is likely to become available to a wider than usual range of staff in different organisations. Therefore, it is essential that thought is given when implementing such data sharing to the implications of potentially different organisational practices and professional obligations of confidentiality.

An implication of the above is that all those involved in developing and implementing the standard will need to give careful consideration to the legal and ethical issues around data sharing. Thought needs to be given at an early stage to the options for assigning different levels of confidentiality to data items or other means of ensuring that only information which is actually needed for patient care is shared in each instance. The potential for misuse of patient information by commercial entities should also be addressed, bearing in mind that for-profit providers of social care are among the target audience. Clear guidance on the confidentiality issues should be produced and incorporated into local data sharing agreements.

The scope of the information implicitly acknowledges that health depends on a complex set of interwoven determinants that are physical, mental, environmental and socioeconomic. While this is very welcome, the resulting detailed 'big data' which could be collected and analysed using innovative methods could produce highly sensitive information. It is important that the potential to benefit the health of the wider community should be realised in this way, but at the same time proper safeguards must be in place and individuals must be made aware of the uses to which their information may be put.

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[1] Regulation (EU) 2016/679 of the European Parliament and of the Council (GDPR): see
https://publications.europa.eu/en/publication-detail/-/publication/3e485e15-11bd-11e6-ba9a-01aa75ed71a1/language-en

C. Responses to the survey questions

We have responded to specific parts of the online survey questions in this section. We have focussed mainly on issues relevant to public health and research, and not answered all of the questions.

Q3. Do you agree that sharing core information will bring these benefits?

We strongly agree that sharing core information as described has the potential to bring all the benefits listed in Q3, though it will not necessarily do so in practice. See further comments under Q4.

Q4. What concerns do you have about sharing core information?

Whether the benefits are realised depends on successful implementation across all the organisations involved at local and national level, and particularly on:

- Well-designed, uniform and smoothly operating national and local arrangements for data sharing across organisational boundaries. Local partners should not have to re-invent data sharing policies and procedures which can be made available at national level, or seek case-by-case approval for particular data flows where national policies and guidelines can facilitate such processes.
- Sufficient resourcing of all local partners to record, manage and use the information effectively. This includes developing the IT capacity and data collection practices of the social care sector, which is of course a major task which will take time and effort. There will also need to be a shared culture around information sharing and understanding of the uses different organisations have for the information.

The benefit of supporting better care planning and research in particular is one which we consider of great importance, and which will not happen without specific efforts to support it. The conditions to achieve the benefit include:

- As mentioned above, local data sharing agreements and national processes for access to data for public health and research purposes which allow information to flow where and when it is needed for 'secondary' uses, without burdensome procedures.
- Structuring and recording of the information according to national standards, including accepted codes and classifications, to ensure consistency and facilitate analysis.
- Awareness by the staff recording information of the need for completeness and data quality to support wider purposes than immediate patient care.

Q6. Can you see any issues arising as a result of people who use services contributing to and sharing their information?

Yes. We strongly support the inclusion of patient-generated information, but note that it will be important for research use as well as patient care that the source of any information is clearly indicated in the record.

Q7. Sections of the core information standard

While all sections of the record are likely to be valuable, we emphasise the value for public health practice and research of the 'demographic details' and 'social context' information. We have made specific suggestions on the content of these sections in part D of this response.

D. Specific issues and suggestions

Person demographics

Gender and Sex

Care should be taken to ensure that the handling of these variables complies with the standards of confidentiality required by the Gender Recognition Act 2004[2]. Looking at the record as a whole, consideration should be given to the special requirements around data sharing which follow from the Gender Recognition Act 2004 (as amended by The Gender Recognition (Disclosure of Information) (England, Wales and Northern Ireland) Order 2005)[3] and the Human Fertilisation and Embryology Act 1990[4] (as amended by the Human Fertilisation and Embryology Act 2008)[5].

Person's address

The specification of address data should include, in addition to an actual address:

- The type of location, i.e. whether it is a private address or a communal establishment.
- If a communal establishment, (a) the type of establishment, (b) its unique NHS[6] or CQC[7] identifier(s) where appropriate, (c) the past duration of residence, and (d) the expected future duration of residence if known.

There should be provision for (a) recording past addresses where relevant, and (b) recording the circumstances of homeless people accurately.

For purposes of analysis (as well as potentially service provision such as home visits) it is essential for the current address to be complete, including postcode, and validated against a standard database such as those supplied commercially by the Royal Mail[8]. For rural areas especially, there should be provision to record detailed georeferencing data.

Communication preferences

Two distinctly separate components are needed, 'preferred contact method' e.g. email, phone, writing; and 'communication needs' e.g. sign language (which type?), large print.

It would be logical for language preferences and need for interpretation to be recorded here.

Alerts

This could be usefully structured into two or more distinct components, separating medical alerts (e.g. allergies, implants) from access/contact alerts (e.g. keyholder, potential danger to visitors). It would also be useful to have a flag indicating the priority/severity of the alert information.

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[2] https://www.legislation.gov.uk/ukpga/2004/7/contents
[3] http://www.legislation.gov.uk/uksi/2005/916/contents/made
[4] https://www.legislation.gov.uk/ukpga/1990/37/contents
[5] https://www.legislation.gov.uk/ukpga/2008/22/contents
[6] See https://digital.nhs.uk/services/organisation-data-service
[7] See https://www.cqc.org.uk/guidance-providers/registration/what-registration
[8] https://www.royalmail.com/business/services/marketing/data-optimisation/paf#

Consent

The information on consent for information sharing should be explicitly linked to recording of the NHS national data opt-out[9].

There should be provision for multiple entries under this heading, since it may be necessary to record consent or objections relating to:

- Different types of medical treatment.
- Information sharing for different purposes and regarding different specific medical or social issues. As a general principle, consent for information sharing should be as granular as is reasonably feasible, so as to empower the individual patient and maximise the opportunities for valuable use of health data.

Individual requirements

The information collected should include a statement of whether the person is disabled according to the statutory definition of the Equality Act 2010.[10] This is a self-declared status.

The overlap between this section and 'Communication preferences' should be addressed.

Participation in research

It might be logical to group the participation in research information with the 'Consent' section.

More information is needed in this section, such as dates of participation.

Attendance details

An additional item on travel to the attendance/transport needs would be valuable to ensure wider patient needs and potential barriers to contact are understood.

An additional item on needs and intentions for follow-up, including both treatment follow-up and preventive or social interventions, would be valuable for coordination between local health and care services.

Admission details

An additional item on travel to the admission/transport needs would be valuable to ensure wider patient needs and potential barriers to contact are understood.

An additional item on needs and intentions for follow-up, including both treatment follow-up and preventive or social interventions, would be valuable for coordination between local health and care services.

Discharge details

Since admission and discharge form a logical unit, explicit linkage between each 'pair' is necessary.

An additional item on travel from hospital/transport needs would be valuable to ensure wider patient needs and potential barriers to safe and appropriate discharge are understood, as would data on home and social circumstances.

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[9] https://digital.nhs.uk/services/national-data-opt-out-programme
[10] https://www.legislation.gov.uk/ukpga/2010/15/contents

An additional item on needs and intentions for follow-up, including both treatment follow-up and preventive or social interventions, would be valuable for coordination between local health and care services.

Social context

We welcome this section which recognises the importance of social factors. It is potentially valuable for better integration of the efforts of health and social care services and to identify needs for preventive and social interventions as well as healthcare. The section should be structured to make best use of the information available for understanding local population health and the impact of wider determinants, as well as highlighting the issues most relevant to the individual patient.

Occupational history

There should be provision to record the person's occupational history in sufficient detail to:

- Assist in identifying past history or current occupational exposure to health risks.
- Allow coding of occupation, employment status and socioeconomic position, which may be important as risk markers and have value for research and equity purposes. National standards should be allowed for, e.g. the National Statistics Socio-Economic Classifications (NS-SEC) requires at least occupation; whether an employer, self-employed or employee; and whether a supervisor.[11]

Educational history

For children and young people, it might be useful to add exposure to bullying at school and other such problems, either here or in another section.

Lifestyle

It is important that the approach to this area should be in line with established understanding of the social determinants of health and current public health practice.[12] In particular, the language 'lifestyle choices made by the patient' is inappropriate, as it ignores the wider context and can be seen as 'victim blaming'.

Since there are already separate items on 'Alcohol intake' and 'Drug/substance use', we suggest:

- Removing the item 'Lifestyle' and instead adding a specific item on physical activity.
- 'Sexual habits' does not seem appropriate in this context because of its sensitive and potentially intrusive nature – any sexual health issues would be documented in other sections.
- Information such as pets, if relevant to the person's health, could be covered under the item 'Household environment'.

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[11] https://www.ons.gov.uk/methodology/classificationsandstandards/otherclassifications/thenationalstatisticssocioeconomicclassificationnssecrebasedonsoc2010

[12] See e.g. http://www.instituteofhealthequity.org/resources-reports/fair-society-healthy-lives-the-marmot-review and https://www.healthknowledge.org.uk/public-health-textbook/disease-causation-diagnostic/2e-health-social-behaviour

Locality factors (new item)

Within the wider heading of social context, we suggest adding an additional item on 'Locality factors' to record wider place-based and social factors known to affect the person's health or their ability to access healthcare, such as distance from public transport, lack of personal mobility (other than disability recorded elsewhere), lack of access to recreational facilities, and so on.

Risks

This section is of obvious usefulness, but some further clarification of the description would help to make the distinction between the type of risks covered here, and the wider epidemiological concept of risk factors which covers many other issues.

Prevention and health promotion (new section)

In addition to the useful sections such as 'Care and support plan', we suggest a new section to record opportunities for prevention and health promotion identified and relevant actions taken. This could have a similar structure to other sections, including e.g.:

- Date
- Person recording
- Type of opportunity/action
- Target behaviour, situation or outcome
- Actions agreed with patient
- Follow-up plan

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