NIHR | Applied Research Collaboration
East of England

Enabling safe and effective information sharing for health and care research
Final report of the Population Health Data Panel Task and Finish Group

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Background

The use of health and care data for research has been vital in generating knowledge to inform policy and practice.

The landscape relating to the sharing of health and care data for research is complex and changing rapidly.

There are challenges in ensuring that data is shared safely and appropriately in a timely way that meets all legal and good governance requirements but also facilitates research and innovation for the public good.

These issues were discussed by East of England NIHR Applied Research Collaboration Population Health Data Advisory Panel and at a subsequent workshop for information governance specialists.

A task and finish group was established to consider what action could be taken within the to address these issues

Task and finish group

The ToR and membership of the Task and Finish group are appended.

Aims:

- To review the issues and actions identified at the workshop held January 2023 to ensure that these reflect the discussion and that all key points have been captured

- To identify issues and actions that can be addressed at regional and local level and develop a plan to address them. This may include action by the Task and Finish group and or recommendations to others.

- To liaise with national leads in NHSE to escalate any issues that need to be addressed at a national level but also provide regional and local input to national resources where appropriate

- To consider the need for some form of permanent regional group or resource once the Task and Finish group has stood down and make recommendations

Key themes and issues

Understanding and communication
- Need for transparency with patients and public over the use of data for research, ensuring clear legal basis at all times
- Not easy given complexity of data protection legislation and guidance
- For professionals - much uncertainty over when / what circumstances data can be shared, on terminology, on opt out processes and on who to ask
- Results in different approaches in different locations

Workforce
- Lack of staff with specialist IG knowledge to do the necessary risk assessment, means delay in getting feedback on proposals
- Rapid turnover of staff adds further difficulty and delay
- Lack of analytical capacity to do data extracts and safe data sharing
- Specialist support from experienced IG staff makes a huge difference
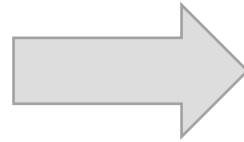
National policy and guidance
- Does not always keep pace with changing practice and local requirements

Group actions

Understanding and communication

Workforce

National policy and guidance

- Extended invitation to join existing regional network of NHS and local authority information governance / data protection leads to include representatives from academic organisations

- Piloting a regional register of information governance / data protection contacts and websites to aid navigation to the right source of specialist advice

- Linked with national lead in NHS England (formerly NHS Digital) to comment on draft guidance extending sublicensing arrangements for data sharing by ICBs to academic organisations

- Exploring a grant application to NIHR Public health Research programme to evaluate My Care Record programme

- Developed recommendations for further action once Task and Finish Group has stood down

Task and Finish group recommended next steps

	Region	System / organisation	National
Understanding and communication	Ensure funding and / or resource is available to secure IG specialist leadership for the regional information governance network as well as administrative support to ensure that it continues as a route for region-wide coordination and national / local communication. This should include maintenance of a regional IG register to facilitate easier identification of key contacts	Ensure IG / data protection leads are linked into the East of England Strategic Information Governance Network (SIGN) to receive latest updates and for peer to peer support (see Appendix for role of SIGN group)	Link with regional networks to ensure ongoing two-way engagement with local systems on issues relating to the use of health and care data for research
Workforce	Deliver a regional workshop on ICB sub-licencing for research to support implementation of data sharing for research via ICB sublicensing, this would include raising awareness of the process and providing guidance on secure data handling for Universities working through the Data Security and Protection Toolkit for first time as well as discussion on approaches to supporting coordination of multi-centre applications	Consider use of generic email for information governance / data protection queries and ensure webpages up to date with latest guidance	Support joint working on information governances issues at regional level to achieve greater consistency in approaches between localities and enable multi-centre research
National policy and guidance	Facilitate the sharing of practice and experience relating to public engagement around data, consider joint approaches to avoid confusion in communications between neighbouring systems	Encourage early and ongoing engagement with IG / data protection team for any project involving data sharing for research	Take action to understand the impact of the new data protection legislation on research for health
	Raise the issue of with specialist IG workforce with the East of England Skills Development Network to that this skills needs this workforce is considered as part of regional delivery	Become familiar with changes to ICB sub-licencing process for data sharing for research and associated requirements	National guidance to highlight importance of local input and sign off on information governance issues
	Support sharing of information on the outcome and impact of research using local data	Support sharing of information on the outcome and impact of research using local data	Support the professionalisation of the information governance / data protection specialist workforce
Who could take action?	Region-wide organisations and bodies including: NHS England, NIHR ARC, Academic Health Science Network, Skills Development Network working with local systems and organisations	ICBs and NHS provider Trusts, local authorities, academic organisations	National bodies

Appendix

Role of East of England Strategic Information Governance Network (SIGN)

Task and Finish group members

East of England Strategic Information Governance Network

Independent from Statutory bodies SIGN provides its membership with a forum to:

- Discuss current issues, best practice, upcoming changes to legislation/guidance/ways of working and how this impacts the work they do in their organisations
- Share best practice.
- Draw on the knowledge and experience of IG colleagues across the region and within national teams
- Receive feedback for national and regional reps NHSE/NDGO/Regional ICS IG Groups
- Means to escalate issues the National Strategic IG Network (SIGN)

Membership is open to IG & data protection professionals from organisations across the East of England, including but not limited to:

- NHS provider trusts
- Local authorities
- Integrated Care Boards
- Healthcare provider partners
- Primary care
- Independent healthcare providers
- Voluntary Sector partners
- Universities
- Independent IG Consultants working with Health Organisations

Task and Finish Group members

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