



# Feedback from Information Governance Working Group

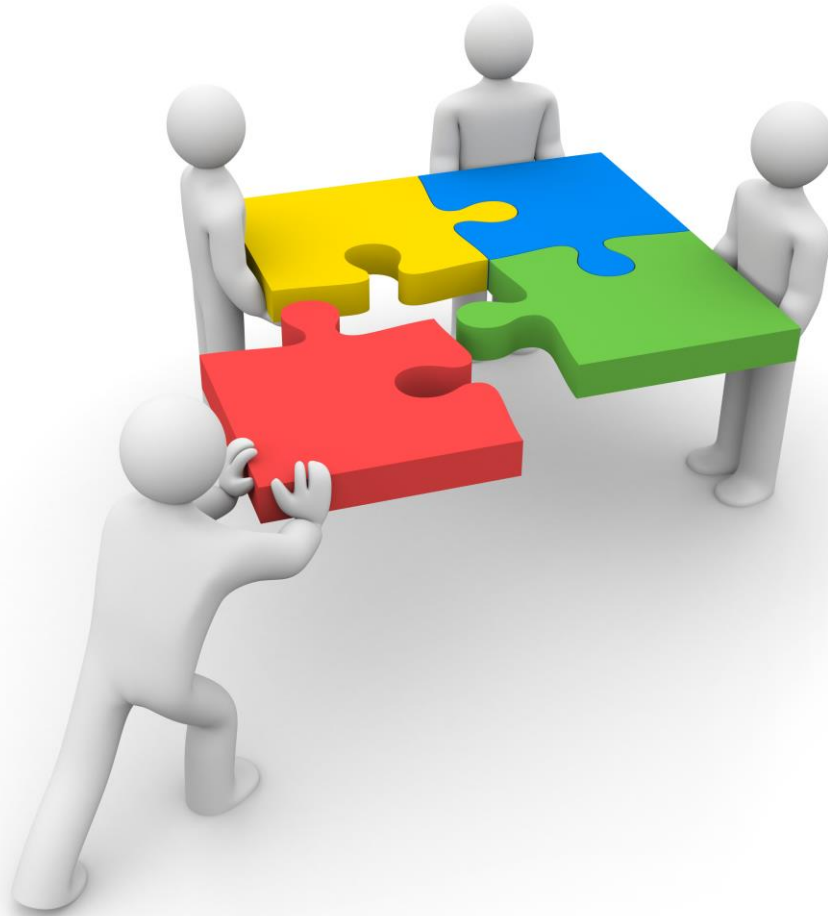
June 2015

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UCL

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The background of the slide features a grayscale image of several interlocking gears of various sizes and a chain drive mechanism. The gears are arranged in a way that suggests a complex mechanical system, with some gears in the foreground and others receding into the background. The lighting is soft, creating a sense of depth and texture.

- About the group
- Recent activities
- Plans



# **ABOUT THE GROUP**

# Purpose

- Liaise with Health and Social Care Information Centre (HSCIC)
- Represent the views of higher educational institutions affected by the IG Toolkit
- Suggest alterations and additions to the Toolkit
- Provide advice and support to HEI specialists working towards Toolkit adoption

# Membership

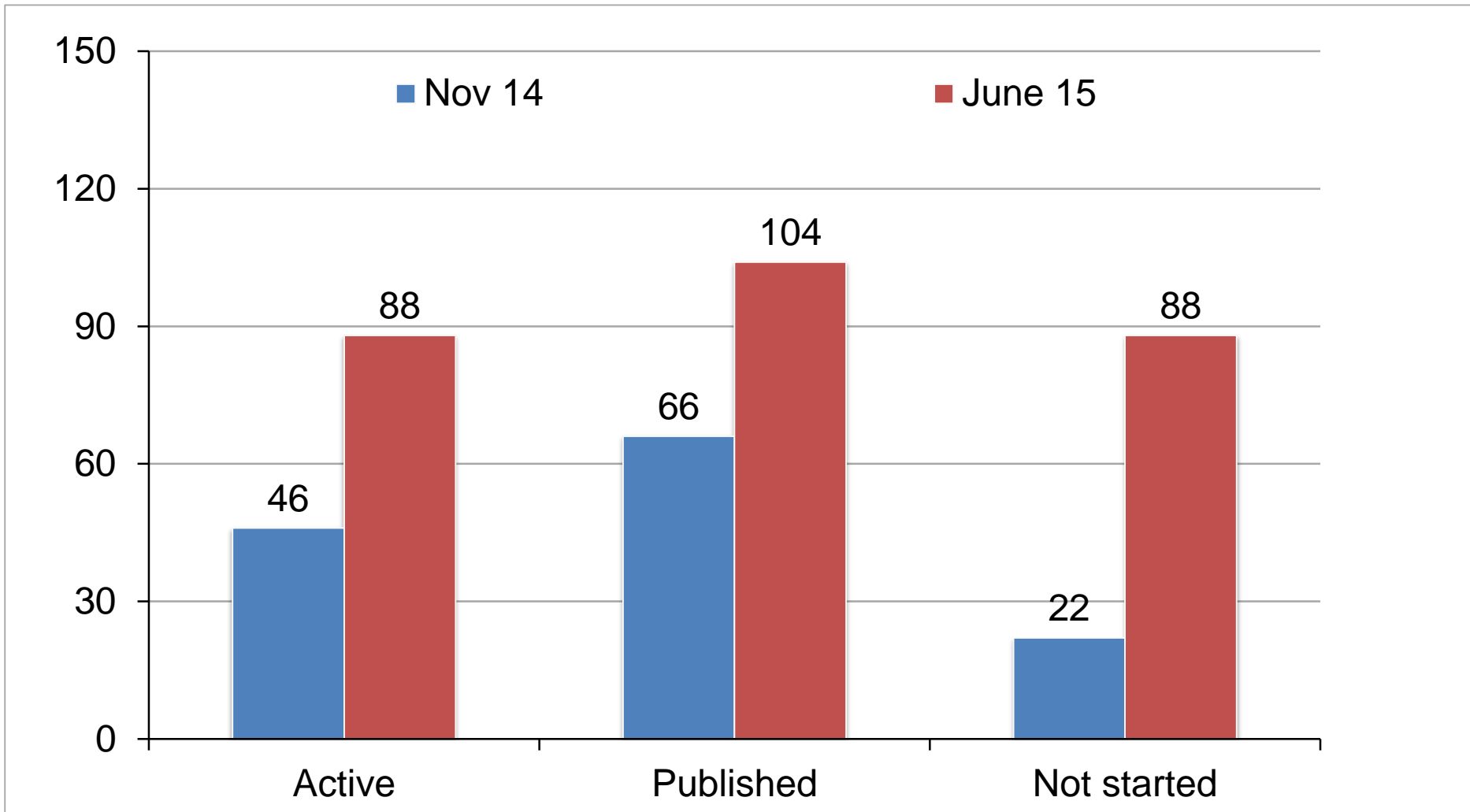
As of March 2015, 71 members representing:

- 22 HEI institutions (was 13)
- 3 Research organisations (unchanged)
- 1 NHS trust
- 1 commercial body
- 1 independent (unchanged)
- HSCIC
- HRA
- JISC



# **RECENT ACTIVITIES**

# IGTK Assessments: HEI (approx)



# IG Toolkit developments

- New version (13) published in June
- New assurance framework (IGAF2) being created:
  - New web page, look & feel
  - More interactive
  - Pages on Caldicott 2 and cyber security
  - Initial focus on NHS Trusts
  - Release October (in parallel)
  - New anonymisation/pseudonymisation standard



# IG Working Group meetings and events

- 8th January: meeting
- 3rd February: workshop and training day
- 17th March: meeting re HSCIC Framework Agreement (FA)
- 31st March: conference call re FA
- 15th May: meeting and IGAF2 workshop

# Other developments

- Regularly attending SIGN meetings
- NIHR IG training course released to WG members
- Letter to be sent by HSCIC to new AND existing IGTK registrants inviting them to join the Group
- Invitation to liaise with HSCIC regarding anonymisation/pseudonymisation standard
- Liaison with HSCIC regarding Framework agreement

# The Partridge Report recommendations

- 1) That the HSCIC undertakes a programme of work to ensure that data has been deleted appropriately for all data releases referenced in the PwC report, where the agreement has ended.
- 2) That the HSCIC develops one clear, simple, efficient and transparent process for the management of all data releases.
- 3) That the HSCIC implements a robust audit function, which will enable ongoing scrutiny of how data is being used, stored and deleted by those receiving it.
- 4) That the HSCIC publishes its policy, process and governance for the release of data.
- 5) That the HSCIC ensures there is clear, transparent and timely decision making, via the appropriate governance for all data releases, and that all decisions are documented and published on its website.
- 6) That the HSCIC implements a robust record keeping approach and that the details of all data releases (including the purpose for which they are released) are made available on its website.
- 7) That the HSCIC develops one Data Sharing Agreement, which is used for all releases of data, and which includes clear sanctions for any breaches.
- 8) That the HSCIC actively pursues a technical solution to allow access to data, without the need to release data out of the HSCIC to external organisations.
- 9) That the HSCIC quarterly Register of all data releases includes the number of law enforcement agencies' person tracing requests processed by the National Back Office. The Register will also include all data being released under NHS IC data sharing agreements, ensuring it is providing a comprehensive account to the public of all data being shared.

# HSCIC Data Sharing Framework Agreement

- Contract created to address the concerns in the Partridge report
- Governs sharing of HSCIC-controlled medical data (ONS, HES etc)
- Intended to create a single "gateway" for requests for personal data by organisations
- Intended to achieve a consistent approach
- Requires IGTK, ISO/IEC 27001 or "other" certification

# Framework Agreement issues

- Contract terms:
  - Scope of applicability (organisation-wide)
  - Assumption of strongly centrally controlled organisation
  - No provision for charitable institutions
- Signing:
  - Some institutions have signed, and some have not
  - Serious problems in getting data (in some cases)
- Engagement:
  - Introduced rather suddenly
  - Original strongly stated HSCIC aim to work with institutions to devise a common document
  - Subsequent revision of position to "no change to the documents in use, and retention of multiple versions"



**PLANS**

# Milestones/deadlines

<b>Month</b>	<b>Event</b>
<b>June</b>	<b>Version 13 of IGTK published</b>
<b>August</b>	<b>Deadline for Knowledge Base articles</b>
<b>October</b>	<b>Interim update of IGTK published</b>
<b>November</b>	<b>IGTK workshop (by Working Group with JISC and HSCIC)</b>

# Next steps

- Escalate Framework Agreement issues and attempt to resolve
- Preparation and delivery of Nov training day
- Contribute to development of anonymisation/pseudonymisation standard
- Contribute to upcoming HSCIC satisfaction survey...



# Conclusion



- Successful collaboration with HSCIC on the Toolkit
- Challenges relating to Framework Agreement with HSCIC
- Working Group would propose to continue in operation
  - Review terms of reference
- Contact Malcolm Teague to get involved:
  - [malcolm.teague@ja.net](mailto:malcolm.teague@ja.net)