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Data Access Advisory Group (DAAG) Closure Report

Document management

Revision History

Version	Date	Summary of Changes
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0.2	22/02/17	Updated initial draft
0.3	13/03/17	Updated draft to incorporate final dashboard figures
0.4	21/03/17	Updated draft based on IGARD comments
1.0	03/07/17	Final version approved by IGARD Chair

Reviewers

This document must be reviewed by the following people:

Reviewer name	Title / Responsibility	Date	Version
Vicki Williams	DAAG Secretariat Manager	February 2017	0.1, 0.2, 0.4
Chris Carrigan	IGARD Chair	13/03/17	0.3
Joanne Bailey	Former DAAG Chair	13/03/17	0.3
IGARD Members		13/03/17	0.3
Martin Severs		24/03/17	0.4

Approved by

This document must be approved by the following people:

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Joanne Bailey		Former DAAG Chair	22/03/17	0.4
Chris Carrigan		IGARD Chair	03/07/17	1.0

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1. Background

The Data Access Advisory Group (DAAG) was established in September 2010 by what was then the NHS Information Centre. DAAG was established to provide independent advice on applications for Hospital Episode Statistics (HES) and the Mental Health Minimum Data Set (MHMDS) involving sensitive data and reviewing the appropriateness of the consent model adopted by applicants for the Data Access Request Service (DARS). DAAG met monthly and consisted of four members, chaired by Executive Director Mark Davies.

The review of NHS Information Centre data releases in June 2014, led by Sir Nick Partridge, highlighted lapses in the governance around data disseminations from the then NHS Information Centre. This, in combination with other factors, led to the re-establishment of DAAG as a larger and more independent committee that could provide effective review of applications for data and help improve the general public's trust in NHS Digital's decision making process around data disseminations.

The expanded DAAG was asked to provide independent scrutiny to a wide range of data flows including the Secondary Uses Service (SUS). In addition following the closure of the General Practice Extraction Service Independent Advisory Group (GPES IAG) in June 2015, DAAG also took on the role of considering requests to disseminate primary care data.

DAAG's membership was initially expanded to include two additional independent members, for a total of six members, and additional independent members were recruited over time as well as an independent Chair. DAAG has represented a strong commitment to openness and transparency and the minutes of all DAAG meetings were published online so that the general public and any interested parties could have sight of what applications had been reviewed, what points had been raised and what recommendations had been made.

2. Reason for closure

In summer 2015 NHS Digital undertook a consultation with the public on a proposal to establish IGARD with an expanded, more independent remit than the existing DAAG. The intention of this change from DAAG to IGARD was that with an expanded remit, IGARD could increase transparency, accountability, participation, quality and consistency; therefore helping strengthen public confidence in NHS Digital's work and enhancing NHS Digital's public reputation. IGARD was designed to have an expanded remit to provide oversight of NHS Digital data disseminations, and is fully independent with no NHS Digital members.

Following the outcome of this consultation DAAG transitioned to the Independent Group Advising (NHS Digital) on the Release of Data (IGARD) on the 1 February 2017; the final DAAG meeting took place on 31 January 2017.

3. DAAG membership

DAAG was chaired from April 2014 onwards by Alan Hassey. Joanne Bailey then accepted the role of independent DAAG Chair from February 2016 and chaired the group until Chris Carrigan, IGARD Chair, assumed the role of chair on 22 December 2016.

From its relaunch as a more independent group (April 2014 onwards), the following individuals have acted as DAAG members at various points in time:

- Alan Hassey (*NHS Digital*)
- Patrick Coyle (*independent*)
- Sean Kirwan (*Department of Health*)
- Dawn Foster (*NHS Digital*)
- John Craven (*independent*)
- Eve Sariyannidou (*independent*)
- Joanne Bailey (*independent*)
- James Wilson (*independent*)
- Peter Short (*NHS Digital*)

4. DAAG in numbers

Following DAAG's transition into its more independent, expanded format in early 2014, application tracking and reporting mechanisms were introduced in September 2014. In the 29 total months between that point and the final DAAG meeting:

- **120** DAAG meetings were held.
- **862¹** applications were reviewed.

For the final year of DAAG's operation (January 2016 – January 2017):

- **53** DAAG meetings were held.
- **359** applications were reviewed, incorporating **958** unique applicant organisations.
- **92%** of applications were either recommended for approval, or recommended for approval with caveats.²

Further details can be found in [Appendix A](#).

5. DAAG Secretariat

From DAAG's transition in 2014 onwards the Secretariat has consisted of two core members of staff: a Secretariat Manager and a (Senior) Secretariat Support Officer. In January 2016 the DAAG Secretariat staff became part of the wider IG ISA team and IG ISA colleagues have had involvement in areas of DAAG processes, such as the review of CCG privacy notices, but Secretariat services have continued to be provided by the two core Secretariat staff. This has resulted in some resource pressures, particularly while undertaking IGARD recruitment and transition activities alongside standard weekly DAAG processes, and steps have been taken to recruit additional support for the IGARD Secretariat.

Despite resource pressures the DAAG Secretariat has consistently delivered to the agreed weekly timescales for DAAG meetings including issuing meeting papers two working days in advance of meetings, producing draft minutes to a high quality standard each week, and publishing documents within the agreed publication scheme timescales. The IGARD

¹ This figure incorporates a large number of group applications that are only counted singly, and does not accommodate for applications that were reviewed multiple times by DAAG.

² This figure incorporates instances where an application was initially deferred or DAAG were unable to recommend for approval, but where an updated and re-submitted application was recommended for approval.

Secretariat will produce a Secretariat Standard Operating Procedure to help ensure continuity and consistent processes in the event of staff absence, new staff training or similar eventualities. The Secretariat Standard Operating Procedure will include agreed SLAs and KPIs to track team performance.

6. Highlights and innovations

Following its relaunch in 2014 DAAG has succeeded in processing a consistently high volume of applications in order to meet business requirements. Whereas the earlier DAAG met monthly and considered up to approximately eight applications per month and the GPES IAG reviewed up to four applications per month, the re-launched DAAG provided capacity to consider up to 14 applications each week.

From September 2014 onwards DAAG have been asked to give advice on numerous study consent materials. Advice given has led to a variety of improvements being made to consent materials and therefore to patients being better informed about the use of their data.

DAAG has facilitated improvements to CCG privacy notices, after concerns were raised that these generally did not meet the standard that the general public would expect in order to clearly inform patients about the use of healthcare data. Based on DAAG advice NHS Digital established a privacy notice review process and has continued to work with NHS England colleagues to encourage CCGs to update their privacy notices so that patients can continue to be accurately informed.

From 2014 DAAG has consistently pushed for improvements to the quality of applications and emphasised the need for each application to unambiguously describe the purpose and processing that will take place as well as providing specific details about outputs and benefits. With DAAG's guidance and through the hard work of DARS and other teams, significant improvements have been made and there is now agreed standard wording to cover a number of important points such as restricting data access to only substantive employees of the organisations involved. This improved application quality should help facilitate the NHS Digital audit process, by allowing auditors to have a clear and unambiguous record of how data should be processed, as well as improving transparency as clearer information is made available through the data release register.

Over DAAG's lifetime NHS Digital has almost always followed DAAG's recommendations, with a small handful of exceptions where DAAG was always informed of the reasoning behind NHS Digital's decision. This speaks to the quality of DAAG's recommendations and the consistent regard that NHS Digital has shown for the group's independent advice.

7. Challenges and lessons learned

In March 2016 DARS undertook an applications migration from the previous Word-based applications system to DARS Online, a CRM-based system. This system has offered a number of important advantages, such as the ability for all relevant staff to access a single, definitive copy of an application, increased tracking and document management capabilities and a clearer audit trail of document updates. However the migration created some short-term challenges as the number of applications submitted to DAAG was limited significantly during the migration period. This was managed through the cancellation of one DAAG meeting, and through DARS prioritising the applications submitted to the surrounding DAAG meetings. The use of CRM has also caused some longer-term challenges for DAAG as the

system does not include the facility to show tracked changes. This has impacted on the review of any returning applications following previous DAAG review, as either applications need to be manually edited to draw attention to amended sections or DAAG needed to re-review the entire application which would increase the amount of time spent on each application and increase the risk of new issues being raised that were not part of the previous review. It is hoped that future releases of DARS Online/CRM may include the ability to display tracked changes as this would likely be a significant benefit to IGARD's future review processes.

Over the history of DAAG there have been ongoing problems relating to the quality of applications; given that each application is owned by the individual applicant, there can be significant variation in the quality of information provided despite the best efforts of the DARS team. DAAG has produced guidance for applicants on key topics such as patient consent, privacy notices and the use of honorary contracts, and there has been a continual focus on improving application quality, while being mindful of the need for consistency and to avoid 'moving the goalposts'. The IGARD Appeals Process specifically states that inconsistency with previous recommendations is an appropriate reason for an applicant to appeal, and it is anticipated that IGARD will be mindful of the need for consistency of recommendations while also recognising that some issues and approaches may develop over time. The Pre-IGARD review process should help to maintain the quality of applications and ensure as much consistency as possible, with the support of the IG Advisor to IGARD and of the Deputy Caldicott Guardian.

There have been specific challenges around Data Services for Commissioners applications, particularly relating to CCG privacy notices and to the significant volume of applications that required review in mid to late 2016. In order to meet NHS Digital commitments regarding CCG applications there was a significant peak of application submissions around July – October 2016, and two additional DAAG meetings were scheduled solely to review Data Services for Commissioners applications in an effort to support these commitments. This peak of applications appeared to have a knock-on effect on application quality, and presented difficulties for out of committee review. At present it is thought that this application peak was a one-off event, but thought should be given to how IGARD would handle a similar spike in application numbers.

The out of committee review process has at times presented challenges, particularly when a high volume of applications have been submitted for out of committee review of caveats. Given the independent nature of DAAG members, out of committee reviews require members to manage their workload around other external work commitments and there have at times been delays when a quorate number of members were not available to review an out of committee application within the expected timescales. This challenge has been exacerbated by some applications being submitted for out of committee review without the necessary clarity about how caveats have been addressed. In some instances the Director of Data Dissemination took the decision to sign off application caveats rather than following full DAAG review out of committee and these instances were notified to DAAG. Concerns around the out of committee process and the importance of processing caveats quickly led to the creation of the IGARD Out of Committee Standard Operating Procedure, which provides greater clarity on what type of recommendation conditions should require out of committee review and what type of amendments are suitable to be addressed by NHS Digital without further IGARD review.

8. Closure activities

8.1. Management of open actions

Actions that remained open at the end of the final DAAG meeting have been migrated into the first IGARD meeting action log to ensure that these are not lost. The Deputy Caldicott Guardian agreed to work with colleagues to address longstanding actions so that these can be closed as soon as reasonably possible.

8.2. Outstanding caveats

As of 1 February 2017, a total of 57 applications had been recommended for approval with caveats by DAAG but had not yet been returned out of committee to address the outstanding caveats. A significant proportion of these applications were from Data Services for Commissioners, with the outstanding caveats relating to privacy notice review.

The former DAAG members who are joining IGARD, plus the IGARD Chair, will continue to review these outstanding caveats in the first instance to attempt to reach a quorate response. However all IGARD members will have sight of the out of committee responses to caveats and will be given the opportunity to respond. In the event that a quorate response can't be reached from former DAAG members, IGARD members will also be asked to review the applications. If a quorate response still cannot be reached then the IGARD Chair may be asked to take action on a particular application.

8.3. Mailbox management

A separate IGARD mailbox has been created for use from 1 February 2017 and NHS Digital colleagues have been informed of the new mailbox address. The DAAG mailbox will continue to be monitored for an appropriate period of time, then archived. Prior to archiving the Secretariat will establish a forwarding rule with an out of office message to remind anyone emailing the DAAG mailbox that they should now contact the IGARD mailbox.

8.4. Website updates

The NHS Digital website was updated on 1 February 2017 to reflect the launch of IGARD and remove previous DAAG information that is no longer relevant, such as previous DAAG member biographies. The updated website includes the IGARD Terms of Reference, IGARD member names and brief biographies, and it is anticipated that the IGARD Standard Operating Procedures will be published following their final approval and ratification by IGARD.

8.5. IGARD launch communications

NHS Digital staff were informed of the IGARD launch on 1 February 2017 via an internal news story featured on the intranet front page. An external new story was published in early February to announce the launch, and the NHS Digital Twitter account tweeted about the launch with a link to this story.

IGARD members have expressed an interest in communications and it has been suggested that they share the external news story with their own contacts to increase awareness.

8.6. Document retention and storage.

All DAAG documentation will be stored on the DAAG SharePoint site for a minimum of twelve months after closure; data retention beyond this period will be considered by the Secretariat and the IGARD Chair.

The SharePoint site will initially remain accessible to IGARD members to assist the transition and educational process for new members, but access may be restricted to only specific NHS Digital employees after twelve months have passed or documents may be archived in a different location at this point. It is anticipated that in future IGARD will move to use Virtual Boardroom rather than SharePoint to manage meeting papers.

Appendix A: Final DAAG Dashboard

Final DAAG Dashboard

January 2016 to January 2017

Background information

January 2016 – January 2017

- Number of DAAG meetings during the period Jan 2016 – Jan 2017: **53**
- Number of applicants considered Jan 2016 – Jan 2017: **958**
- Number of applicants considered out of committee Jan 2016 – Jan 2017 by Members: **557**
- Average number of applicants considered by Members per meeting (Jan 2016 – Jan 2017): **18**
- Average number of applicants considered out of committee by Members per week (Jan 2016 – Jan 2017): **10.5**

Chart 1:

Proportion within recommendation decision per application as at 31 January 2017 and for the final meeting of DAAG.

Please note a number of applications are still showing as 'caveat outstanding' due to the fact that a number are group CCG applications where only a certain number within the group have met all caveats including privacy notice caveats and SIRO email issued – the tracker is per application not applicant.

Progress is ongoing to finalise outstanding caveats.

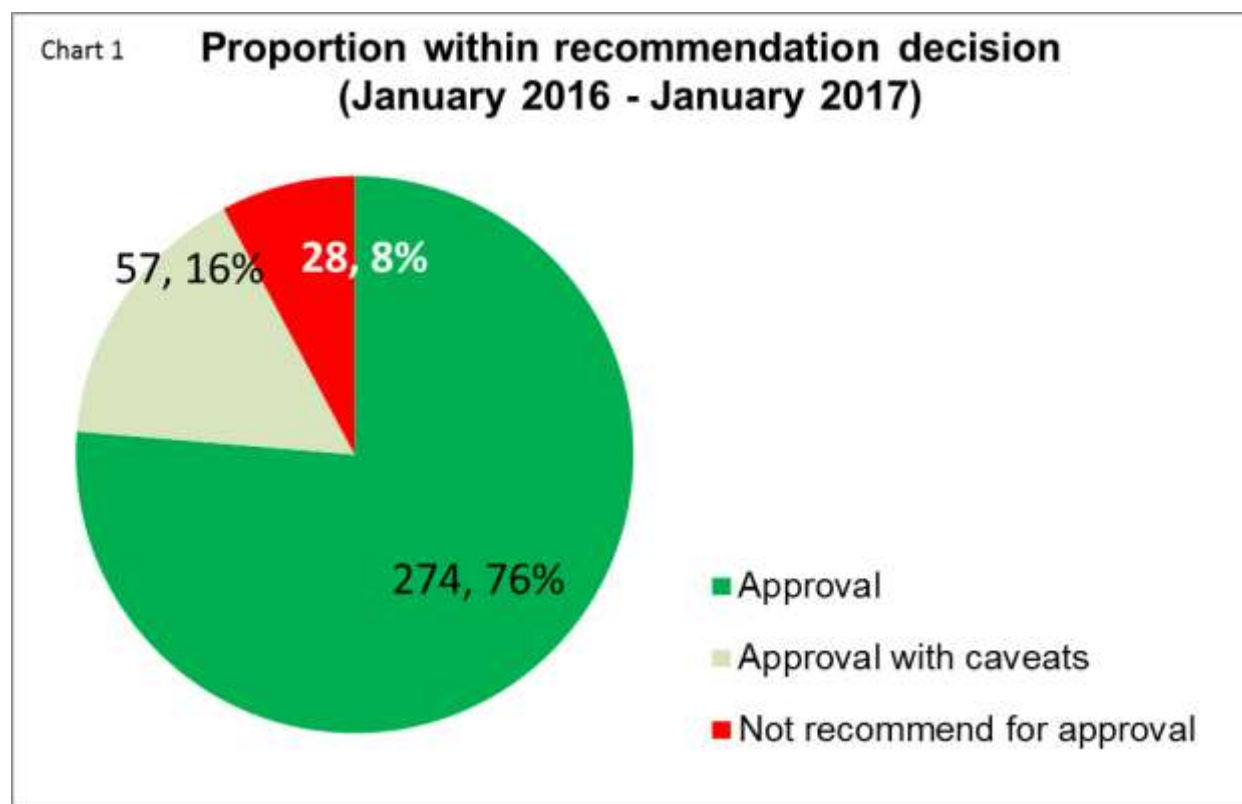


Chart 2:

Recommendation by application type as at 31 January 2017 and for the final meeting of DAAG.

Progress is ongoing to finalise outstanding caveats.

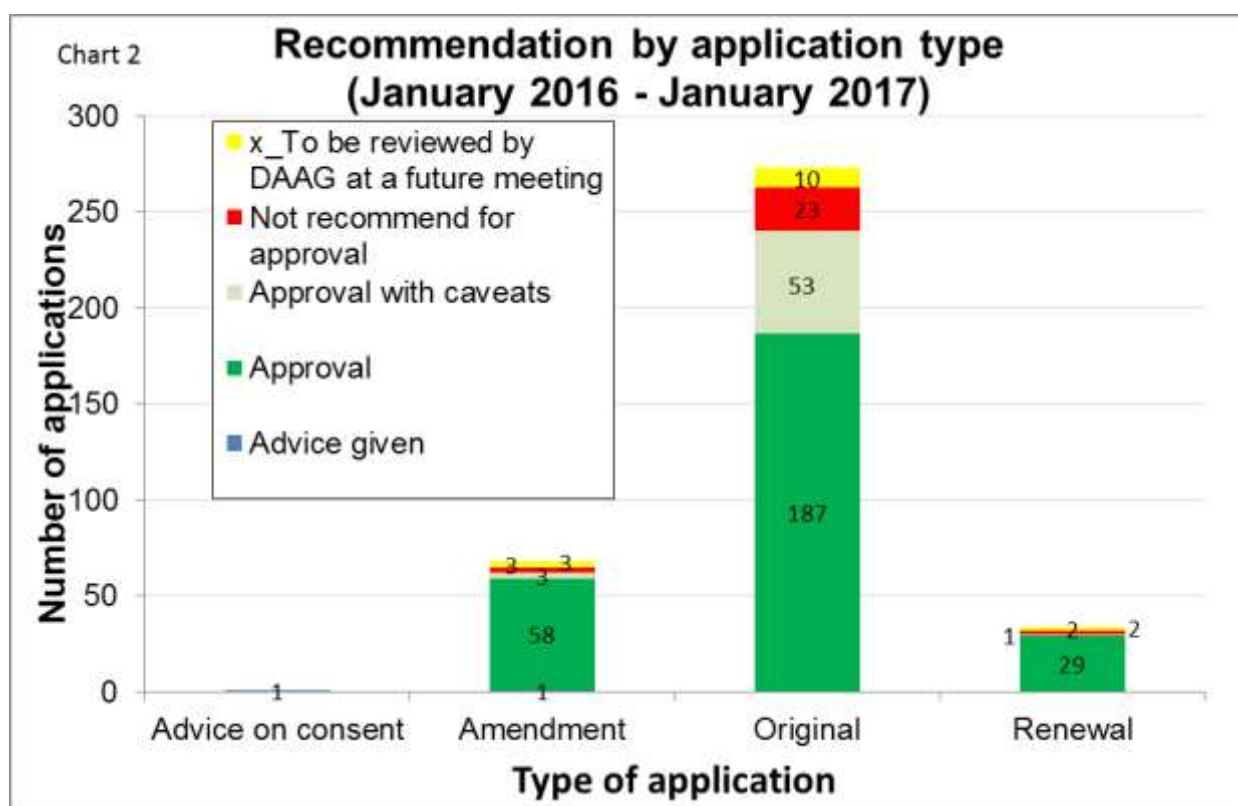


Chart 3:

DAAG decisions by month per application as at 31 January 2017 and for the final meeting of DAAG.

Please note a number of applications are still showing as 'caveat outstanding' due to the fact that a number are group CCG applications where only a certain number within the group have met all caveats including privacy notice caveats and SIRO email issued – the tracker is per application not per applicant.

Progress is ongoing to finalise outstanding caveats.

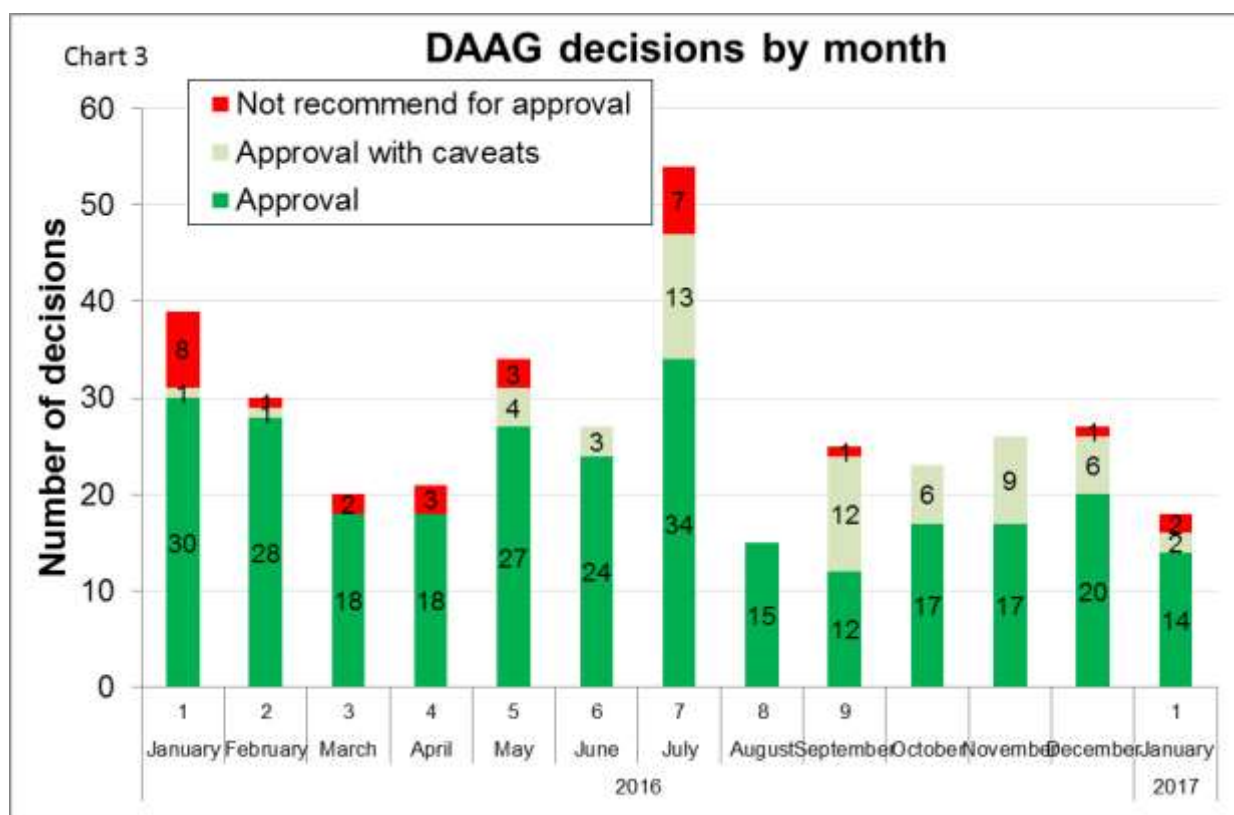
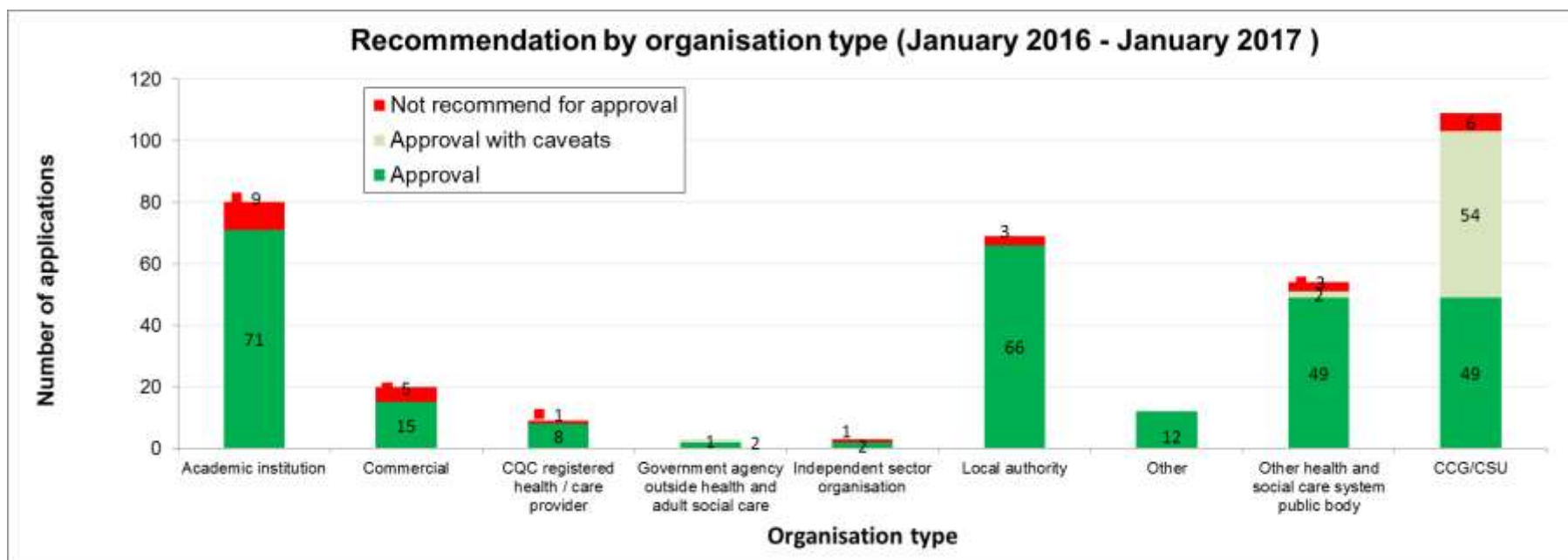


Chart 4:

Recommendation by organisation type per application as at 31 January 2017 and for the final meeting of DAAG.

Please note a number of applications are still showing as 'caveat outstanding' due to the fact that a number are group CCG applications where only a certain number within the group have met all caveats including privacy notice caveats and SIRO email issued – the tracker is per application not per applicant



Appendix B: You Said We Did

The 'You Said We Did' report for the IGARD consultation is available on the NHS Digital website published alongside this report.