

# Information for Quality programme: update

**Strategic delivery:**       Setting standards       Increasing and informing choice       Demonstrating efficiency economy and value

## Details:

Meeting      Authority

Agenda item      7

Paper number      HFEA (16/11/2016) 813

Meeting date      16 November 2016

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## Output:

For information or decision?      For information

Recommendation      The Authority is asked to note:

- Progress since the last Authority meeting, noting the launch of the HFEA website and Clinic Portal
- The delays to Release 2 – the new data submission system
- Our emerging information policy
- Programme budget.

Resource implications      No additional resource implications above that already budgeted

Implementation date      During 2016–17 business year

Communication(s)      Regular, range of mechanisms

Organisational risk       Low       Medium       High

Annexes:      Information Policy draft: respective responsibilities

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## 1. Background

### 1.1. The Information for Quality (IfQ) programme encompasses:

- The redesign of our website and Choose a Fertility Clinic (CaFC) function
- The redesign of the 'Clinic Portal' (used for interacting with clinics) and combining it with data submission functionality (Release 2) that is currently provided in our separate system (used by clinics to submit treatment data to us)
- A revised dataset and data dictionary which will be submitted for approval by the Standardisation Committee for Care Information (SCCI)
- A revised Register of treatments, which will include the migration of historical data contained within the existing Register
- The redesign of our main internal systems that comprise the Authority's Register and supporting IT processes.

### 1.2. Given the importance of IfQ to our strategy, we update the Authority on progress at each meeting and seek approval for direction and actions.

### 1.3. This paper updates Members on:

- Concluding the Programme
- Work in progress
- Release 2 – data submission development
- Our emerging information policy
- Programme budget

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## 2. The IfQ Programme

### 2.1. The IfQ Programme is scheduled to conclude in March 2017. As this is the last meeting of the Authority this calendar year and given the approaching financial year-end, this paper both brings members up to date with progress and identifies the critical next steps as regards programme delivery. A fuller discussion will be presented to the next meeting of the Audit and Governance Committee in December.

### 2.2. As stated at previous meetings IfQ has been developed according to an 'agile' methodology required by the Government Digital Service (GDS). This methodology divides programmes into a number of stages. IfQ is currently at the 'public beta' stage, which involves going public with a beta version, receiving feedback and preparing to go live. This is followed by a final 'live' stage – a tested solution that is ready to release and then continuously improved. This latter reference, to continuous improvement, is an important feature. The IfQ Programme needs to close for funding and governance purposes, but that does not mean that there will be no further work on the various elements of the programme. On the contrary, GDS expectations assume a different way of working with a focus on meeting user needs through

'continuous' feedback and, where necessary, improvement. Our business planning processes – our funded programme of activity within the HFEA to meet our strategic objectives – will need to adapt accordingly.

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### 3. Work in progress

- 3.1.** The period since the last meeting of the Authority has seen the continuation of an intense period of activity by the teams. The work has been progressed due to the substantial efforts of the many people working in the HFEA and our partners.
- 3.2. Website and choose a fertility clinic:** these two products were released to public beta in July 2016. Feedback has been positive and is discussed in detail in an accompanying paper to this meeting. However, as reported at the September meeting of the Authority we now propose that both the website and CaFC do not proceed to live until February 2017. This is in recognition of the Judicial Review, which is scheduled to take place on 19 and 20 December 2016, and the need to secure final GDS approval which is currently planned for late January 2017.
- 3.3.** For the purposes of the Programme the website and CaFC is largely concluded, and the additional design and development work that needs to take place is already included within the existing contract. Subject to assessment the product will be live in February 2017 – and the current HFEA website decommissioned.
- 3.4. Clinic Portal (Release 1):** this element of the portal will allow clinics to conduct all transactions with the HFEA (other than for treatment data submission) – applying for a new licence, PGD condition and so on; seeing their performance on a range of measures on an enhanced dashboard; being able to find regulatory requirements using an enhanced search facility; two-way communications between us and clinics, and so on. The report to the September meeting of the Authority confirmed that the portal was released in beta form on 12 July 2016, and anticipated that the GDS assessment was scheduled to take place on 28 October 2016.
- 3.5.** A consequence of the beta testing (and, to a large extent, its purpose) was the identification of issues and bugs and the resolution of these has required more time and effort than expected. As a consequence, we have decided to reschedule the GDS assessment – now 21 November 2016 – so that further and final user testing could be undertaken on 3 November 2016.
- 3.6.** For the purposes of the Programme the Clinic Portal (Release 1) is, subject to GDS assessment, largely concluded. It is expected that the Clinic Portal will be released as live in December 2016 and the current portal decommissioned.
- 3.7. Clinic Portal Release 2:** This is the component that replaces the current clinic data submission application (EDI, or, for the majority of clinics, bespoke

electronic patient record systems (EPRS)). This is a substantial undertaking requiring both extensive foundational work and a new 'front end' service that will be experienced by clinic users. Much of the foundational work is well advanced – as reported to previous meetings of the Authority. We have designed a new Register database with a new data structure, with each item defined in a data dictionary, which is in the process of being accredited by NHS Digital. We are finalising the cleansing of vital data prior to the migration of the current Register database, and that Register migration process is backed by a Register migration strategy. And we are developing a set of new expectations as regards clinics' information management arrangements once we move to the new database. More detail is provided in section 4 below.

- 3.8.** This work underpins the 'front-end' service as experienced by clinic users. At the previous meeting of the Authority it was reported that our end-October 2016 release expectations would not be met for EDI users, albeit our original expectations for clinics with EPRS of 31 March 2016 was achievable. We expect to launch EDI at the same time although there are operational benefits in not implementing the two variants at the same time. We continue to consider this.
- 3.9.** In summary, proof of concepts and business processes have been mapped – and tested with clinic users, and act as the specification to the developers who are making steady progress building the 'input questions' and screens that clinics will utilise.
- 3.10.** Challenges remain with this aspect of the Programme. While much of the foundational work has progressed well over a significant period of time it is likely that the remaining work will absorb the majority of the remaining time and resource attached to the Programme.

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## **4. Release 2 – data submission development**

As outlined in 3.7 above, there has been much progress, with more to do, on the necessary foundational work in transforming the data submission system.

### **Data dictionary and accreditation**

- 4.1.** The data dictionary – the basis of all the information we need to collect and the definition of each field is complete, and is the basis for the components of information set out in 3.9 above.
- 4.2.** The Standardisation Committee for Care Information (part of NHS Digital) accreditation process for the 'UK ART dataset' and its implementation is on-track. It is an intensive process requiring the submission of substantial documentation considered by several committees but is a good external test of the thoroughness by which we have gone about our work.

### **Data 'cleansing'**

- 4.3.** Over the last 12 months, the Register has been subject to a thorough overhaul, or cleansing exercise. As the data moves from the current Register structure or

database to a new more efficient database, to allow for much greater ease of interrogation and less manual intervention, it is vital that critical fields are reviewed for error, absence or duplication and resolved – as far as possible.

- 4.4.** We identified 14160 fields or records requiring intervention, and there are now fewer than 800 where additional intervention is necessary – a manageable sum.
- 4.5.** Within this sum is the work that clinics must undertake. Since April 2016 we have incrementally returned records to clinics which have problems, usually outcome forms where the treatment forms is missing. The team worked very hard to minimise the burden and sent back only 354 records to clinics. Over half of these reviews have been completed and there is steady progress on the balance.

#### **Register data migration**

- 4.6.** Due to the importance of the Register and the highly sensitive nature of the data contained within it, a well-managed and successful data migration process is central to realising many of the anticipated benefits of the IfQ Programme.
- 4.7.** Our migration strategy required a foundational ‘health check’ of the data to be conducted, which identifies data quality issues at the outset of the project. Following the health check of the data, the strategy requires five separate data migration ‘loads’ of all of the historical data in to the new Register structure.
- 4.8.** It was expected in the Summer that the migration would have been completed, in line with the timetable for introducing the new data submission system. This is predominantly a task that needs to be undertaken by skilled and experienced staff in the HFEA. The knock-on effects of delays to the website (particularly choose a fertility clinic, and the Clinic Portal) has meant the migration work has slowed.
- 4.9.** That said, trial load 1 has been successfully completed and the team is currently finalising the reconciliation and migration exceptions reports in the lead up to commencing subsequent work

Assurance of this careful progress will be provided by Programme oversight, which in turn will receive a report from an independent data management specialist, commissioned to provide reports to the Authority.

#### **Information policy**

- 4.10.** Clearly, there has been a substantial investment by the HFEA in developing a new information architecture that relies on licensed clinics to meet our information management expectations of them – such that the benefits anticipated by the investment can be realised. We have no reason to doubt that they will not. Equally we want to take the opportunity to renew our expectations of them.
- 4.11.** We will want to develop a set of principles to underpin the HFEA’s approach to information and how they support the delivery of our strategic objectives recognising the increasing role digitisation is playing in facilitating choice and

access, supporting research, improved safety and outcomes and reducing treatment delivery costs.

- 4.12.** Due to the somewhat inefficient nature of the current submission system and Register structure there has been a blurring of lines of accountability between the HFEA and clinics in relation to clinics' performance in submitting timely data, of the right quality, and dealing with errors promptly. This necessitates a careful and cautious approach by our compliance and audit teams as regards escalation of concerns. In a regulated environment this is far from ideal.
- 4.13.** The new data submission system will require less resource for both clinics and the HFEA. As such this presents a good opportunity to recalibrate and make very clear the respective responsibilities, of the HFEA and licensed clinics. A draft information policy will be presented at the January 2017 meeting of the Authority setting this out in greater depth - but our thinking on establishing clearer responsibilities is set out at annex A, for early comment.

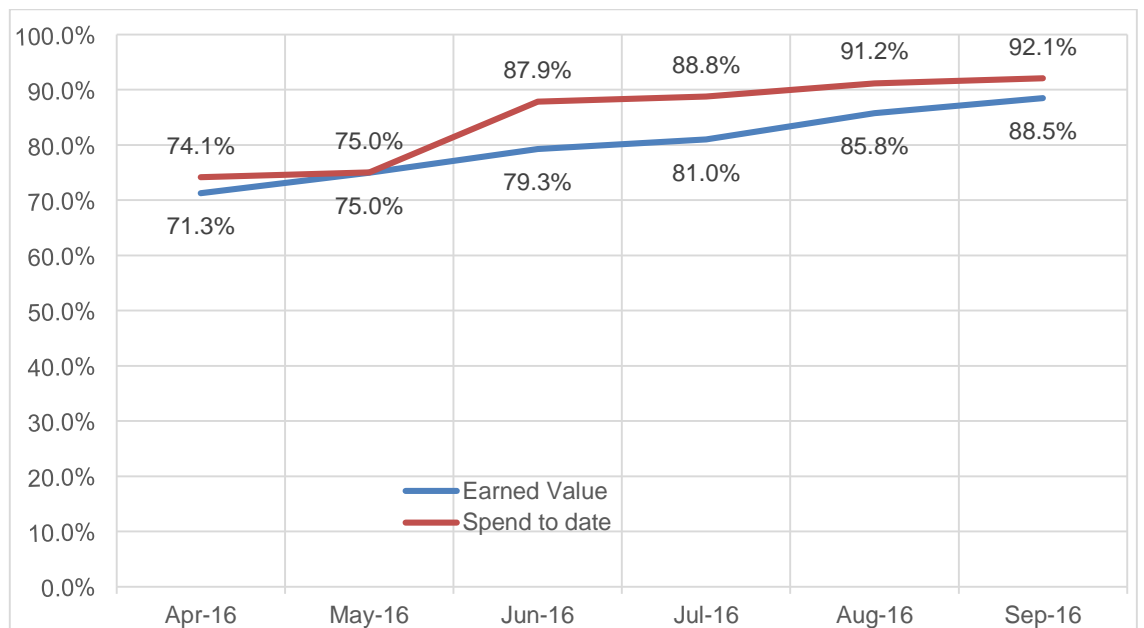
## 5. Programme budget

- 5.1.** As reported previously, a revised IfQ programme plan was finalised and signed off by the IfQ Programme Board in January 2016, in line with the overall £1.134m agreed by Authority. We do not expect the Programme will exceed this figure at 31 March 2017.
- 5.2.** This month variance is explained by an underspend originally forecasted for the security consultant. The underspend should balance in the upcoming months once the work is completed and invoiced.
- 5.3.** The current budget position for 2016/17 is as follows:

Total IfQ budget May 2016	Budget this FY (16/17)	Planned spend (Sep 16)	Actual to date (Sep 16)	Monthly Variance
1,227,402	£619,025	£1,111,888	£1,132,111	£20,223

- 5.4.** The spend to date has increased slightly between August and September and is now again joining the earned value. As we reach the end of beta and complete the live phase we expect the earned value to reach its peak reflecting the work completed.

Period	Apr-16	May-16	Jun-16	Jul-16	Aug-16	Sep-16
Earned Value	70.0%	75%	79%	81%	91.2%	92.1%
Spend to date	74.1%	75%	87%	88%	85.8%	88.5%



## 6. Recommendation

### 6.1. The Authority is asked to note:

- Progress since the last Authority meeting, noting the launch of the HFEA website and Clinic Portal;
- The delays to Release 2 – the new data submission system
- Our emerging information policy
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**Annex A – Information Policy draft: respective responsibilities**

HFEA	Licensed clinics
Register data submission	
<p>to provide clear definitions and justifications for the data to be submitted and ensure it is consistent with the Standardisation Committee for Care Information (SCCI) UK ART information standard;</p> <p>to consult sector representatives before changing data elements and carefully consider the balance of the additional benefit changes confer to users of the data collected and the impact of changes on the sector who supply it;</p> <p>subject to statutory, regulatory and provision of information requirements to consult the sector prior to setting or changing data submission timeframes;</p> <p>to minimise the administrative consequences of register data submission;</p> <p>to clearly specify the minimum technical/software requirements for register data submission;</p> <p>to respond to requests for technical and non-technical support within 48 hours where requested via official support channels;</p> <p>to promote technical interoperability and wherever appropriate adopt open standards;</p> <p>to provide suppliers of third-party data submission systems with at least 6 months' advance notice of changes they may need to make to their software to maintain compatibility with changing data submission requirements and to provide them with the information necessary to make the changes.</p>	<p>to submit register data in the form and at intervals specified by the Authority in Directions.</p>
Data quality	
<p>to promote data quality by provision of mechanisms to: reject data and require re-submission where it fails to meet the minimum quality standards; minimise input</p>	<p>to correct error identified in submissions within the period specified by the Authority in Directions.</p>



<p>error; identify error in a timely way; and ease of error correction;</p> <p>to provide transparency with respect to data held by the HFEA to the licensed centres that have submitted it along with the ability to extract and use the data submitted in a common format;</p> <p>to disclose the status/quality of the data published to licenced centres and users of register information via use of status messages; caveats; data quality metrics;</p> <p>to review and report on information performance as part of our overall inspection assessment;</p> <p>where data quality issues give rise to particular concern and/or remain unaddressed, to take corrective action in accordance with the HFEA's compliance and enforcement policy.</p>	<p>to apply the quality management requirements detailed in licence conditions to data submission processes;</p>
Data publication	
<p>The Authority publishes extracts of Register Data in the form of 'Choose a Fertility Clinic' pages on its website (<a href="http://www.hfea.gov.uk/guide/">http://www.hfea.gov.uk/guide/</a>), which is updated regularly;</p> <p>to disclose to a licenced centre in advance of publication, the data to be published about it along with the basis and reasons for any processing of the date;</p> <p>to allow a reasonable time between notification of data to be published for centre review, update and feedback to the Authority to ensure the published data is accurate;</p> <p>to disclose the status/quality of the data published to users (e.g. published as clinic confirmed, unconfirmed by clinic, caveated and/or with data quality metrics).</p>	<p>to review the data to be published and to correct it/inform the HFEA of any inaccuracies within the timeframe specified in Directions;</p> <p>to confirm\verify that the data to be published is complete and accurate by the date required by the HFEA.</p>