

Intelligence Strategy 2017-2020

Strategic delivery:

Safe, ethical, effective treatment

Consistent outcomes and support

Improving standards through intelligence

Details:

Meeting	Authority
Agenda item	9
Paper number	HFEA (24/01/2018) 866
Meeting date	24 January 2018
Author	Caylin Joski-Jethi, Head of Intelligence

Output:

For information or decision?	For decision
Recommendation	The Authority is asked to comment on and approve the HFEA's Intelligence strategy for 2017-2020.
Resource implications	In budget
Implementation date	Throughout 2017/18-2019/20 business years.
Communication(s)	Publication on HFEA website.
Organisational risk	<input type="checkbox"/> Low <input checked="" type="checkbox"/> Medium <input type="checkbox"/> High
Annexes	Annex A: Intelligence Strategy 2017-2020

1. Summary

- 1.1. Our 2017-2020 vision for high quality care for everyone affected by fertility treatment sets out a bold new ambition to improve standards through using intelligence.
- 1.2. We recognise that we are ‘information rich’. We maintain the world’s foremost Register of fertility treatments, have a unique insight into fertility clinics through our regulatory function, interact with patients, stakeholders and the public through various channels, and hold a range of other specialist knowledge. The new Intelligence team has been created in the recognition that improvements will not come from information alone, but from high quality analysis and an organisation-wide focus on using this information to make decisions which improve standards for patients.
- 1.3. This strategy sets out how we will build on the successes of the Information for Quality programme, supporting the organisation to get the most value out of the new clinic portal and website, enhanced patient feedback mechanisms, the restructured Register of treatments and outcomes, and new data submission system.
- 1.4. This Intelligence strategy places patient experience at its heart by developing services which enable patients to act as their own advocates and involving them in shaping aspects of sector development. This reflects our aim to recognise that patient experience, alongside the expertise of care professionals, is a valuable tool that can be used to improve standards. We will also use the full extent of our organisational knowledge to ensure robust evidence is used by all stakeholders to drive sustainable self-improvement in clinics.

2. Development of the strategy

- 2.1. The Intelligence team developed its strategy through a process of reviewing existing systems and worked closely with teams across the organisation to identify areas to build upon.
- 2.2. We also took advantage of early opportunities to gain input into the strategy with key stakeholders, which included the Scientific and Clinical Advances Advisory Committee (SCAAC), Authority and members of the research community. This means elements of the strategy have already been agreed in principle by the Authority.
- 2.3. We would like to thank everyone involved in developing the strategy, recognising that it required significant investment beyond everyone’s existing workloads. We are confident in our strategic direction, and ready to agree the final document so that we can begin delivering the outcomes we have committed to, and subsequently publish it on our website.

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- 2.4.** The executive's corporate management group (CMG) has agreed the approach, and considered the implementation of the strategy across the next two annual business plans through to the end of the 2017-2020 strategy.
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3. Delivery of the strategy

- 3.1.** The Intelligence team's ability to deliver the strategy relies upon strong collaborative relationships and robust information sharing processes across the HFEA.
- 3.2.** Our commitments in the Intelligence strategy (Annex A) are aligned with the aims set out in our 2017-2020 organisational strategy. A summary of the Intelligence strategy is provided below, and a few elements are discussed in detail.
- 3.3.** We set out a programme of publications which respond to emerging policy areas, feedback from patients and enhance related workstreams, such as ensuring greater awareness of research and evidence-based practice.
- 3.4.** We will deliver on two programmes of work relating to good value fertility services: one, working with NHS England and others to promote equality of access and incentivising improved performance; and the second, to inform future discussions around HFEA fees, ensuring we continue to recover the full cost of regulation and provide value for money.
- 3.5.** We aim to synthesise the broad range of evidence held across the organisation, using this to enhance our understanding of factors driving changes in performance and being responsive to emerging needs, resulting in more targeted interventions and patient information.
- 3.6.** We will work in partnerships with patients and individuals affected by assisted reproduction to understand their experiences, perceptions and needs. We will use this to inform our publications and incentivise improved quality of patient care in clinics.
- 3.7.** We will capitalise on recent system improvements to deliver more standardised approaches to information sharing and provision, facilitating relationships with the research community, and working with data producers, users and stakeholders in other organisations to meet best practice standards and deliver joined up approaches to problems.
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4. Patient-focused publications

- 4.1.** The strategy contains a proposal for two new publications whose scope and titles are in development.

Media stories and research: what does the evidence tell us?

- 4.2.** This report will provide a 'myth-busting' approach to public information needs, offering a patient-friendly evidence-based discussion around stories and perceptions within the media. This aims to promote greater societal awareness of evidence-based practice, support our wider work relating to treatment add-

ons, raise understanding of the role of research in driving improvements and fulfil our commitments to ensure patients can make informed choices.

Patient voices: what does good practice in clinics look like?

- 4.3.** This report will build on feedback from patients, inspectors and the information available on the new website, drawing together the factors that patients should consider when choosing a fertility clinic and highlighting examples of good practice. It could provide an evidence-base for patients against which to benchmark elements of patient care being offered at clinics, helping patients to advocate for improved services and incentivising a more equitable experience across the UK.

5. Patient care quality mark

- 5.1.** This proposal builds upon the principles of co-production, which is gaining increasing popularity across the public sector, particularly within health, social care and education.
- 5.2.** Co-production is defined¹ within the Care Act as when “an individual [influences] the support and services [they] receive, or when groups of people get together to influence the way that services are designed, commissioned and delivered”.
- 5.3.** Co-production acknowledges that individuals affected by ART have knowledge and experience that can be used to help make services better, not only for themselves but for other people who need them. It means that power is shared more equally between those who use services and those who provide them.
- 5.4.** There is currently no blueprint for high quality patient care above and beyond compliance with the Code of Practice, however, through working in partnership with patients, it is believed we could create a framework of commonly agreed principles which define excellent patient care.
- 5.5.** This proposal for a ‘patient care quality mark’ recognises that for patients, regulatory compliance against the Code of Practice only forms part of their experience, satisfaction and outcomes.
- 5.6.** The quality mark would be a voluntary scheme for those clinics that want to benchmark their patient care quality. Once clinics are able to demonstrate they have met the framework criteria, they can be assessed and awarded the mark.
- 5.7.** We recognise the long-term commitment of this proposal, the need to engage widely with the sector, the public and individuals affected by ART, and the need to pilot and scope a range of options for delivery.
- 5.8.** It is important to note that this is not proposed as a regulatory requirement for clinics and that there will be involvement from a range of stakeholders in determining the framework to ensure that patient expectations and desires are

¹ Department of Health. (2014). Care and Support Statutory Guidance: Issued Under the Care Act 2014

not prioritised above clinical safety or other relevant issues. There is also a need to recognise that this proposal represents a longer-term project that may not be fully completed, or improvements realised, within the period covered by this Intelligence strategy.

5.9. Some of the potential options for design and delivery could include:

- partnering with a patient-advocacy group to aid in delivery and roll out of the framework
- introducing 'patient inspectors' who could assess clinics against the framework
- embedding the patient care quality mark within the existing inspection process

5.10. Expected benefits of delivering a patient care quality framework under the principles of co-production include:

- delivering a framework which clinics can use to audit, plan and evaluate their services
- supporting our leadership drive in which PRs should aspire to excellent quality care for patients
- power and control is fairer and more equally shared to ensure that individuals affected by fertility treatment have a say in deciding how services should work
- giving clinics the confidence that their service is based on evidence informed by patients
- improving the experiences of people using services provided for ART
- building stakeholder networks and ensuring that assets, including individuals, are better valued and used

6. National patient survey

6.1. The intelligence strategy offers a commitment to help clinics gain more value from their own feedback by, for example, facilitating a national patient feedback survey. This proposal could gather opinions from patients about their experience of fertility treatment, asking them to provide honest feedback on their experiences.

6.2. It could provide an influential source of public information about fertility treatment and offer patients a collective voice to help shape the future of the sector and their institution for current and future patients.

6.3. Results from the survey could help provide a broader picture of the quality of fertility services across the UK which would complement our clinics level patient feedback mechanisms, raise awareness of the HFEA and our role, and raise awareness of the CaFC Rate Your Clinic pages.

6.4. Additional benefits from a national patient survey could include:

- Clinic-level data used to identify areas of strength and weakness, and used to effect changes designed to improve patient experience
- Reduced variation nationally in the quality of patient care
- Results feeding into the HFEA's quality assurance and inspection process to target the inspection process
- Validating our CaFC patient feedback and inspection processes to ensure that patients are able to make informed decisions

7. Next steps

- 7.1.** The strategy, once approved by the Authority, will be published on our website and used to inform our programme of work until 2020.

8. Recommendation

- 8.1.** The Authority is asked to comment on and approve the HFEA's Intelligence strategy for 2017-2020.

Intelligence Strategy 2017/18-2019/20

Improve standards through intelligence

Our 2017-2020 vision for high quality care for everyone affected by fertility treatment sets out a bold new ambition to improve standards through using intelligence. We define intelligence as going 'beyond the data', turning insight - gained from synthesising and analysing a broad range of information - into actionable recommendations for how we, as an organisation, can improve standards.

We recognise that we are 'information rich'. We maintain the world's foremost Register of fertility treatments, have a unique insight into fertility clinics through our regulatory function, interact with patients, stakeholders and the public through various channels, and hold a range of other specialist knowledge. The new intelligence team has been created in the recognition that improvements will not come from information alone, but from high quality analysis and an organisation-wide focus on using this information to make decisions which improve standards for patients.

This intelligence strategy places patient experience at its heart by developing services which enable patients to act as their own advocates and involving them in shaping sector development bridging the gap between patients, the HFEA and clinics to improve standards. Alongside this, we will use the full extent of our organisational knowledge to ensure robust evidence is used by all stakeholders to drive sustainable self-improvement in clinics.

Principles upon which we will work

Impact: we will pursue ideas and work in ways which generate impact for patients, the sector and society as a whole

Transparent: we will share knowledge within the context of promoting an open, enquiring, and informed society, recognising that this fosters the progress of research and benefits patients, the sector and society as a whole

Targeted and accessible: we will ensure the information and services we provide are evidence-based, accessible and that more people receive the information they need in a meaningful way

Collaborative: we will build strategic partnerships within, and external to, the HFEA and foster excellent relationships with patients to promote sustainable sector-wide improvement

How we will achieve our aim

Our aims support our 2017-2020 strategic objectives and describe how we will work towards our vision by focusing on patient experience and sector-level monitoring.

Aim: Use our data and intelligence to drive quality improvements for patients

What will we do?

Publish high quality and accessible information:

- Fertility trends report on treatment outcomes
- State of the fertility sector report on performance in clinics and laboratories
- Treatment specific information, such as on egg freezing and donor conception treatment
- Media stories and research: what does the evidence tell us?
- Patient voices: what does good practice in clinics look like?
- Ad hoc briefings on emerging topics of interest

What difference will it make?

- We will be more focused on analysing information and using what it's telling us to inform our priorities, policies and future work
- Patients will be informed in an accessible and meaningful way about the effectiveness and safety of services
- Clinics will be able to benchmark their performance and identify how to self-improve
- People will continue to turn to us for clear, unbiased and trusted information
- There will be evidence to drive change and inform public and sector debates

Aim: Patients and NHS commissioners receive good value fertility services

What will we do?

- Work with NHS England and other organisations to deliver a benchmark price, commissioning guidance and outcomes-based tariff
- Explore the views of patients on their financial expectations and experiences
- Share benchmark data with NHS commissioners
- Use available data to understand the factors driving treatment activity and deliver an income forecasting model to inform treatment fees

What difference will it make?

- Reduced variation in the price of treatment
- We will continue to support the NHS in its endeavor to pay a fair price for fertility services
- Patients will have realistic expectations for the cost of treatment
- An evidence-based assessment for future income
- Patients are provided with value for money and transparent information about HFEA fees

Aim: Targeted and responsive regulatory interventions in the interests of quality

What will we do?

- Regularly review enquiries, complaints, FOIs and PQs, incidents, inspection reports, and qualitative feedback from all stakeholders
- Develop key indicators and use these for regular sector-level reviews of statistical outcomes to understand how overall performance is changing

What difference will it make?

- A shared understanding of 'good sector performance' across the organisation
- We will be more focused on analysing information and using what it's telling us to inform our priorities, policies and future work
- Increased quality and consistency across clinics
- Increased value for money

- Develop a more risk-based approach to inspections, where we spend less time on low-risk clinics

Aim: Increase insight into patient experience and encourage good practice based on feedback

What will we do?

- Explore what 'quality care' means to patients and communicate this so that patients are empowered to advocate for improvements
- Co-produce a 'patient care quality mark' with patients
- Develop feedback mechanisms to gain insight from clinic staff, researchers and other stakeholders
- Share patient feedback on how emotionally difficult infertility and treatment can be
- Help clinics gain more value from their own feedback by, for example, facilitating a national patient feedback survey or facilitating links between different clinics

What difference will it make?

- We will introduce new patient-driven mechanisms to incentivise effective, safe, ethical services
- Patients and the public will be empowered to work in partnership with the HFEA to improve priorities that are important to them
- An improvement in patients' experience of treatment
- New and expanded evidence will inform the way we approach quality improvements across the sector
- Clinics will have the ability to benchmark their performance and identify how to self-improve resulting in increased quality of care

Aim: Work more smartly with our resources, and capitalise on recent system improvements

What will we do?

- Build on the capacity of the new website to engage with a wider audience
- Publish more, standardised data internally and externally and in a wider range of formats along with guidelines and standards
- Represent the end user and guide the development of internal reporting tools
- Redesign the application process for using identifying information in research, so more insight can be gained using external, specialist resources
- Develop a new anonymised Register informed by stakeholder engagement
- Ensure compliance with data protection and statutory reporting requirements
- Work more closely with data producers, users, and stakeholders in other organisations to meet best practice standards and deliver joined up approaches to problems

What difference will it make?

- People will continue to turn to us for clear, unbiased and trusted information
- Information is more useful, accessible and consistent in the way it is used and reported
- Improved presentation and public understanding of our published data
- A larger, high quality evidence base, will inform our approach to improving standards across the sector
- Improved and more consistent outcomes in clinics
- Patients will have confidence in their clinic and the HFEA as life-long information guardians
- Provide greater value for money for the HFEA's resources, for patients and other organisations
- Support improved public health decisions