Information Governance Review: Executive Summary

Review of the Information Governance Landscape across Health and Social Care in Scotland

Executive summary
20 July 2021

Acknowledgement

This report would not have been possible without the help and input from **over 100 stakeholders across health and social care in Scotland**, and a network of experts from Scotland, England, Wales, Northern Ireland and the Republic of Ireland, as well as the Digital Health and Care Institute, the University of Edinburgh, the Scottish Government legal team and the Public Bodies Unit.

Contents

Key Points

- Many good things are happening in the information governance (IG) sphere in Scotland.

- We need to move forward from the idea that IG is a barrier – it is a facilitator.

- The government is listening to what people are saying and is working to make improvements and put better processes, tools and resources in place.

- 'Ownership' of IG and any challenges it presents does not lie exclusively with IG specialists – the wider system must recognise its own role and accountability for making IG work.

- This Review informs on options for evidence-based policy learned from the broad IG community and stakeholders in Scotland, as well as from other countries, and makes recommendations for the effective re-design of IG structures and associated processes, while empowering people to manage information and privacy risks and opportunities successfully.

- This Review has enabled clarification of the current IG landscape, its complexities and the needs of the stakeholders and the public. In turn, this has helped to prioritise a national programme of work for further co-design and implementation, along with a breath of stakeholders.

- Recent experiences with COVID have emphasised the importance of quick access to robust data. It also has shown the importance of leadership and a common purpose to make IG work better within complex data flows. This experience is consistent with the findings of the Review of IG in Scotland, and has demonstrated the urgency of implementing the recommendations in the main report.

1. Why did we need a review of information governance?

The people of Scotland expect technology and information systems to be part of how health and care services are delivered, and for that to be a seamless and almost invisible part of the process. To enable this, Scotland needs a streamlined national information governance (IG) approach (see Box 1) that addresses:

- inconsistencies in decisions over the delivery and use of data and digital technologies;
- variation in interpretation of current regulations; and
- the risk appetite among organisations, which can obstruct or facilitate the realisation of benefits from digital and data-driven health and care innovation.

The National IG Review is one of the key IG and Assurance building blocks of the Digital Health and Care Strategy (Figure 1).

★ COVID-19 Accelerated progress

Digital Identity

Data Policy

New IG Framework & Centre of IG Expertise

IG Standards

Information Assurance Framework

IG Competency Framework

Digital and Data Ethics frameworks

National IG Review

Public and stakeholder engagement

Industry contract

Digital Health and Care Strategy
Information Governance and Assurance Building Blocks

Figure 1. Digital Health and Care Strategy IG and assurance building blocks

The IG Review report, of which this is the executive summary, sets out to:

- describe the current IG landscape;
- inform on options for evidence-based policy learned from other countries, as well as the IG community and stakeholders; and
- make a series of recommendations for the effective re-design of IG structures and associated processes, while empowering people to manage information and privacy risks and opportunities successfully.

The Scottish Parliament Health and Sport Committee and other stakeholders have strongly emphasised the need to review how IG could be streamlined at a national level. With more efficient ways needing to be found to assess appropriately how fair, lawful. and secure proposals for digital and data-driven innovation are, and how information and privacy risks can be better managed with greater transparency and public engagement.

Box 1. What is IG?

There is no universal definition of IG. Definitions range from describing IG as a discipline or framework with a focus on sensitive personal data, to the broader application of risk-based privacy compliance across information assets.

The information management professionals' organisation ARMA International describes IG as: "the overarching and coordinating strategy for all organisational information."

The NHS Information Authority (England) defines its scope as "to do with the way the NHS handles information about patients/clients and employees, in particular personal and sensitive information".

The Accenture Institute for Health and Public Sector Value identifies IG with five interrelated disciplines: data privacy, data confidentiality, data security, data quality, and data integrity (Figure 2).
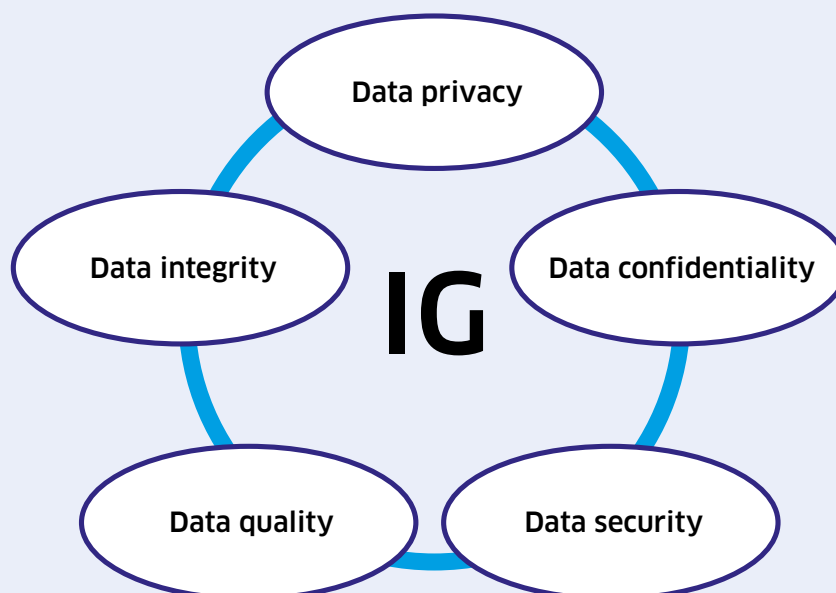
Figure 2. The five interrelated disciplines within IG (Accenture Institute for Health and Public Service Value, 2010)

And ISACA[1], an international professional association focused on IT governance, approaches governance from the alignment of information (and related technology) with the organisation strategy, and involves *"setting direction through prioritization and decision making; and monitoring performance and compliance against agreed-on direction and objectives".*

For the purposes of this review, the working definition of IG amalgamates the concepts and wide scope illustrated in Box 1.

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1 ISACA Interactive Glossary & Term Translations | ISACA

2. Who was involved in the review?

The IG Review was an extensive multi-stakeholder consultation process involving over 100 interviews across health and social care in Scotland, and a network of experts from Scotland, England, Wales, Northern Ireland and the Republic of Ireland. It also involved the Digital Health and Care Institute, the Scottish Government legal team and the Public Bodies Unit.

3. How was the review carried out?

This Review was based on a situation analysis (Box 2). The aim was to identify priorities for delivering an improvement plan for creating a more efficient IG, assurance and security framework across health and social care in Scotland. A desktop exercise was also carried out, examining relevant electronic sources of information. In addition, the Review report reflects earlier work undertaken by relevant colleagues and organisations (a full list of sources can be found in the main Review report).

Box 2. What is a situation analysis?

A situation analysis establishes a clear, detailed and realistic picture of the opportunities, resources, challenges and barriers in the improvement process. The quality of the situation analysis will affect the success of all transformational efforts; therefore, substantial time and resources were invested to allow the best reasonable outcomes.

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4. What did the review find?

4.1 Main conclusions

4.1.1 The IG landscape in Scotland requires more maturity

The current IG landscape in Scotland is fragmented. This means it lacks the consistency to ensure efficient scrutiny and delivery of health and social care digital solutions, and effective access to, and sharing of, data assets.

The ARMA IG Maturity Index offers a source for benchmarking the NHS Scotland IG landscape and the current National IG Programme. Ratings against this Index show that of the seven IG areas identified by ARMA, authorities, capabilities and infrastructure are the most mature (Figure 3).

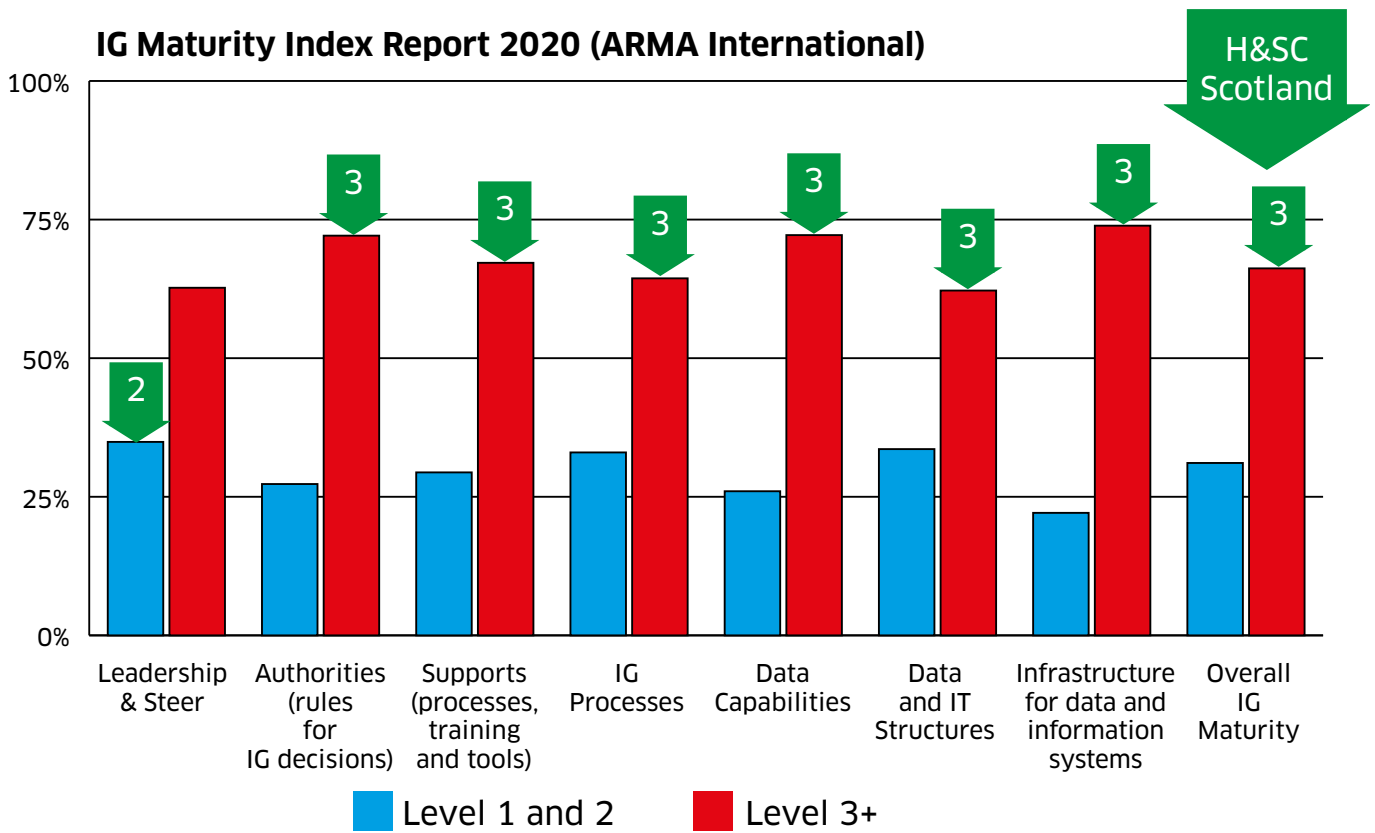**IG Maturity Index Report 2020 (ARMA International)**

Figure 3. Health and social care rankings against the seven ARMA IG dimensions

IG Maturity can be improved over time using the Scottish Approach to Service Design (Figure 4).
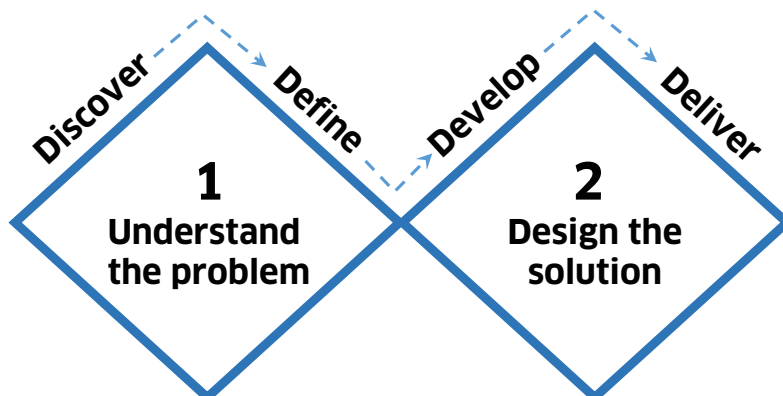
Figure 4. Scottish Approach to Service Design (SAtSD).

4.1.2 Policies, procedures and processes are inconsistent across the IG landscape.

An IG locus exists in both government and health and care settings, but the IG landscape is significantly complicated.

It is difficult to visualise and manage risk at both local and national level due to inconsistencies in the approaches across organisations. The existing federated IG model in Scotland, with high levels of local autonomy, has led to less standardisation and integration and higher costs. The results are:

- varying interpretation of regulatory frameworks and risk appetites;
- increased synergies through regional clusters, localities and relationships established during the COVID-19 pandemic;
- complex and dynamic data-control relationships; and
- scattered, inconsistent and erratic decision-making routes.

Complicated transparency arrangements make it a virtually impossible task for the general public to engage with IG in health and social care.

Some common IG roles exist across health and care organisations, but there is a need to harmonise the scope of key roles' functions and responsibilities, training and continuing professional development activity, professionalise the IG world and empower people to manage information risk better.

Inconsistencies in policies, procedures and processes across the IG landscape are resulting in frustrations around cross-boundary work.

As part of the IG Review, the NHS Scotland International Engagement Team set up a Five Nations IG Collaboration Group (involving participants from England, Wales, the Republic of Ireland, Northern Ireland and Scotland) to compare and contrast key areas of the IG landscape. All nations have a series of IG structures covering strategic direction, advisory, operational and monitoring functions, but they seem to have highly complex IG landscapes.

IG operations (in areas such as privacy, transparency and ethics) are scattered across a range of different data controllers (Box 3). There are many IG tools, but they can be unfocused, inconsistent, inefficient and insufficient. This inherent complexity results in:

- a fractured and inconsistent route to data;
- missed opportunities for greater interoperability and resilience of information systems; and
- a lack of transparency.

In turn, these difficulties raise the level of overall information risks in the system. They make it difficult to have visibility and manage potentially negative impacts, and lead to missed opportunities for the positive use of data and digital technologies.

Box 3. What are data controllers?

Data protection legislation in the UK defines who is (or becomes de-facto) data controller and data processor. The **data controller** (such as a health board or a general practice) makes decisions over the "purpose and means" – "why" and "how" the data is processed. **Data processors** act on behalf and under instruction of a data controller (the level of direction required is not evident within current legislation)[2]. These are functional concepts, in that they aim to allocate responsibilities according to the actual roles of the parties.

Assessing the existence of joint participation and convergence in the decision-making process is becoming crucial in complex IG settings, such as health and care in Scotland.

4.1.3 Scotland's response to COVID-19 has accelerated IG transformation

More responsive, user-centred services that cover a spectrum of needs are now being developed, primarily in response to the COVID-19 pandemic. The digital and data solutions delivered during COVID-19 have followed the stages set out in Figure 2 in an extremely condensed and rapid fashion.

Culture and behaviour, however, remain significant barriers to change. COVID-19 nevertheless has accelerated the digital transformation of health and care and the IG way of working across NHS Scotland and potentially social care. Models used for the COVID-19 pandemic, such as the Data and Intelligence Network (Box 4), ways of scaling up and rapidly delivering telehealth and telecare solutions, and participatory governance used for programmes such as vaccinations (Box 5), should be expanded to other areas.

Box 4. What is the COVID-19 Data and Intelligence Network?

The Scottish Government set up the COVID-19 Data and Intelligence Network to minimise the spread of COVID-19 in Scotland by quickly identifying COVID-19 resurgence, clusters and outbreaks, and detecting co-circulation with winter respiratory viruses. Its remit is to protect vulnerable populations, evaluate the impact of COVID-19 on health, care and society and extend the vision to the National Performance Framework. The COVID-19 Data and Intelligence Network includes local and national health bodies, local government, central government, skills and enterprise agencies, Scottish academia and civil society organisations.

Box 5. IG within the Vaccinations Programme.

A multi-layer governance system was set up for various programmes of work, with the involvement of representatives of data controllers and other key stakeholders across health and care. Decisions over data and information systems converge through joint participation at strategic, tactical and operational levels.

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2 Guidelines 07/2020 on the concepts of controller and processor in the GDPR | European Data Protection Board (europa.eu)

5. Main recommendations

The IG Review's recommendations are structured around key elements of the ARMA (Figure 5), Accenture (Figure 2) and the ISACA (Figure 6) IG models.
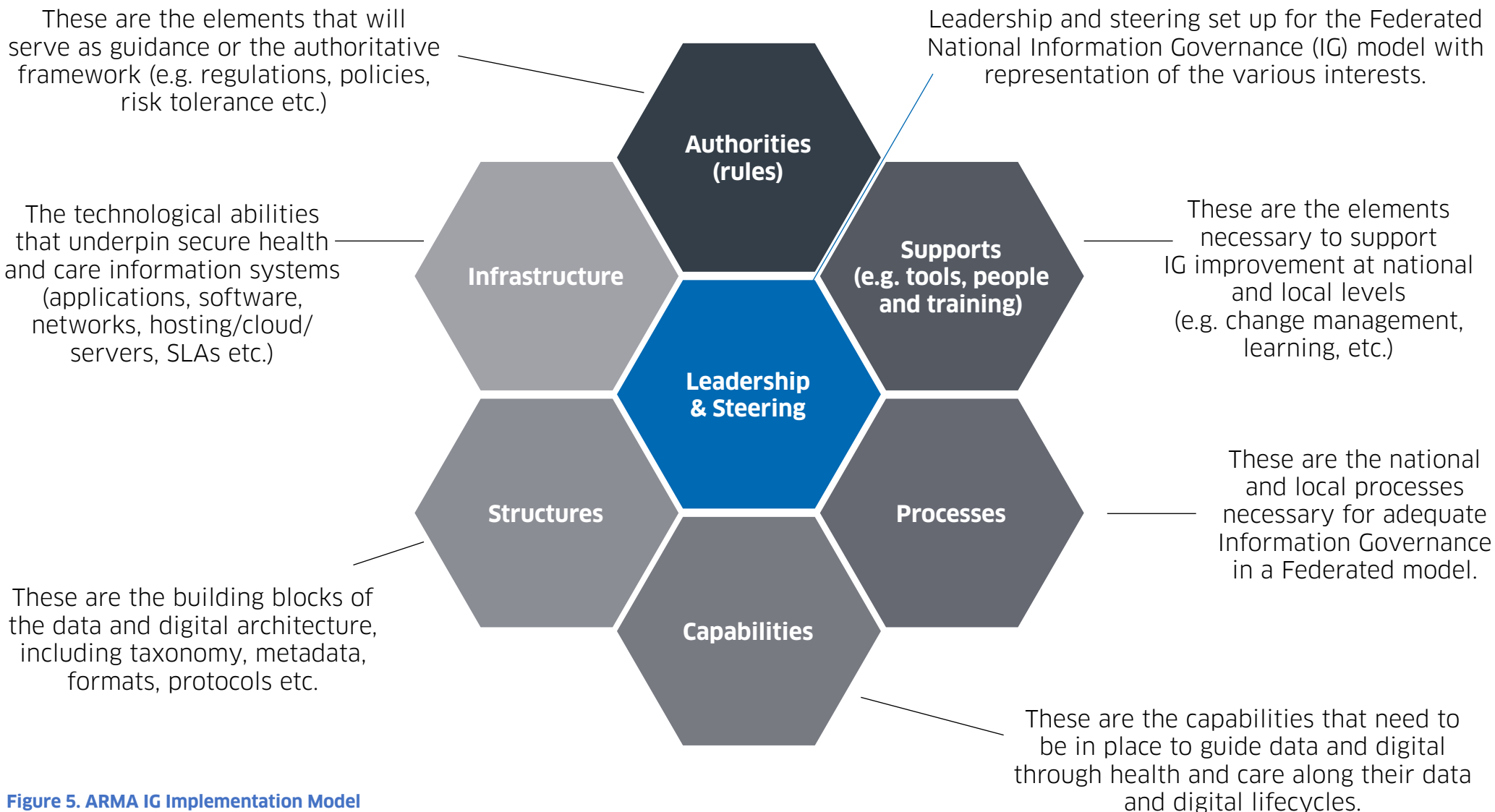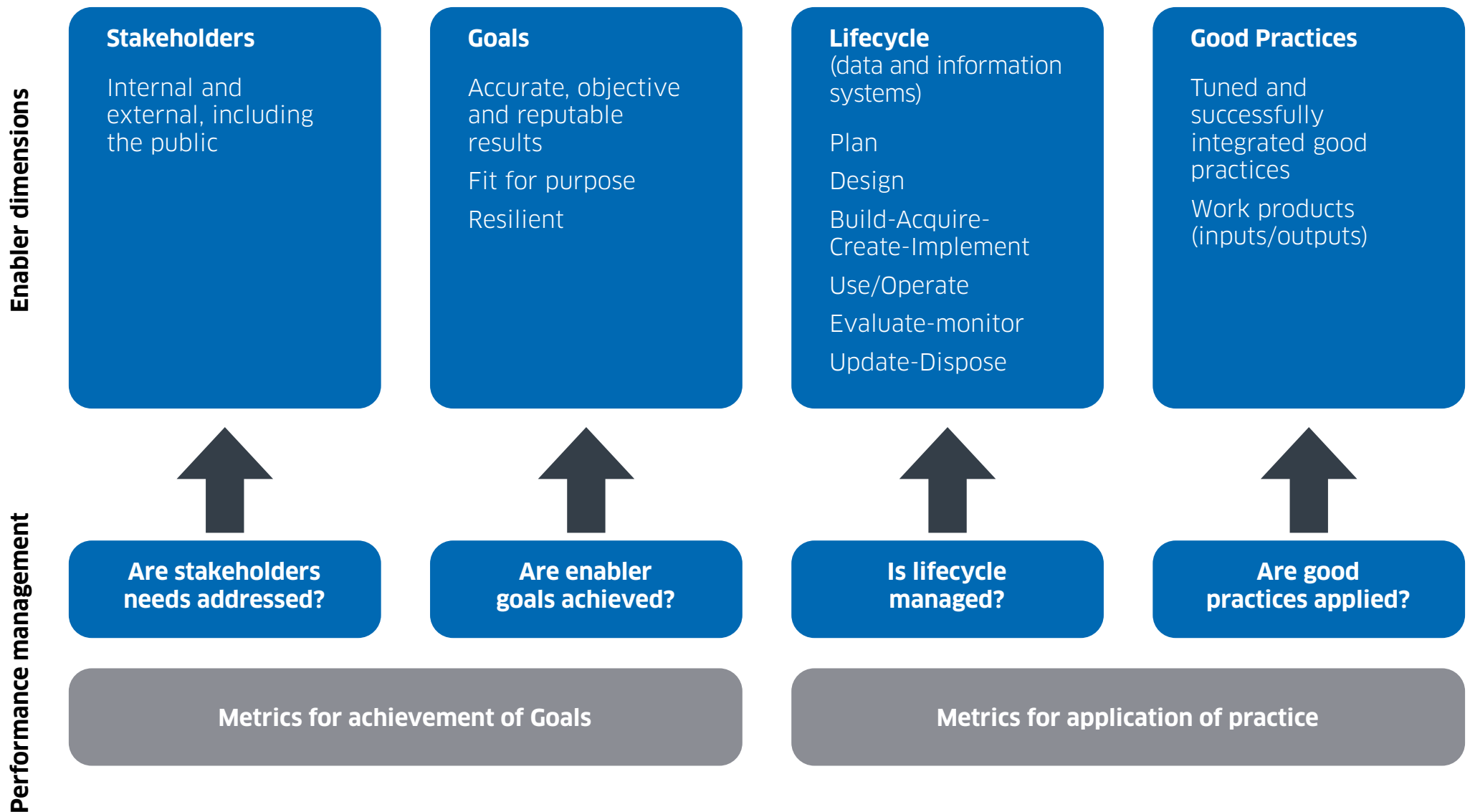
These are the elements that will serve as guidance or the authoritative framework (e.g. regulations, policies, risk tolerance etc.)

Leadership and steering set up for the Federated National Information Governance (IG) model with representation of the various interests.

The technological abilities that underpin secure health and care information systems (applications, software, networks, hosting/cloud/ servers, SLAs etc.)

Authorities (rules)

Infrastructure

Supports (e.g. tools, people and training)

These are the elements necessary to support IG improvement at national and local levels (e.g. change management, learning, etc.)

Leadership & Steering

Structures

Processes

These are the national and local processes necessary for adequate Information Governance in a Federated model.

These are the building blocks of the data and digital architecture, including taxonomy, metadata, formats, protocols etc.

Capabilities

These are the capabilities that need to be in place to guide data and digital through health and care along their data and digital lifecycles.

Figure 5. ARMA IG Implementation Model

Enabler dimensions

Stakeholders

Internal and external, including the public

Goals

Accurate, objective and reputable results

Fit for purpose

Resilient

Lifecycle
(data and information systems)

Plan

Design

Build-Acquire-Create-Implement

Use/Operate

Evaluate-monitor

Update-Dispose

Good Practices

Tuned and successfully integrated good practices

Work products (inputs/outputs)

Performance management

Are stakeholders needs addressed?

Are enabler goals achieved?

Is lifecycle managed?

Are good practices applied?

Metrics for achievement of Goals

Metrics for application of practice

Based on COBIT 5® Enabling Information and ISO/IEC 38500 definition of governance.

Figure 6. A holistic IG approach (ISACA)

During a workshop for Scottish Government IG professionals, the report's overarching recommendations were ranked based on their importance in meeting the vision, dependencies and quick wins (see Figure 7).

Vision

Streamlined Information Governance (IG) in Scotland, to enable the realisation of benefits from digital and data-driven health and care innovation.

A holistic IG approach to enable end-to-end information across public sector

Main recommendations		
Lead & Steer	**Innovate Co-Produce Scale-Up**	**Demonstrate success and Assurance**
1 Set the National IG Direction for Health & Care	**5** IG People	**9** IG Maturity baseline
2 Engage effectively to co-produce solutions.	**6** IG Processes and structures	**10** Plan for IG improvement
3 Readiness. Prepare.	**7** IG Tools	**11** Monitor IG progress and assurance.
4 Inspire. Motivate.	**8** IG Products (data and digital assets)	**12** Scale IG up.

Figure 7. Summary of the IG Review's key recommendations

Lead & Steer

1 Set the National IG Direction for Health and Care.

Establish a National IG Programme, aligning relevant strategies (e.g. data and digital), strengthening the IG ambition to maximise the realisation of benefits from digital and data-driven health and care innovation.

The National IG Programme should be reviewed on a regular basis in line with the Digital Health and Care and other relevant strategies, adding a "corporate" IG layer to a federated programme of work. This should involve designating clear national roles and lines of accountability at local and national levels; including central accountability and responsibilities for information assets of National value, particularly for the purposes of obtaining assurance at a national level.

The current federated IG model should be adjusted to secure the right balance of centralisation and local autonomy, while improving national leadership (see Figure 8). This would require consideration of:

a. clear lines of accountability,

b. alignment of IG roles and responsibilities,

c. centralisation of some functions and services (e.g. centres of IG expertise, National Information Assurance Officer, National Data Guardian or equivalent) and potentially setting a National IG Body in areas of benefit.

Establishing a federated, de-cluttered IG model would allow autonomous data controllers and various central structures to collaborate to meet the needs of the wider health and care system. Data controllers would also have more influence in large-scale data processing decisions through their participation in various IG groups.

2 Engage effectively for the co-production of IG solutions.

Prepare for change and co-production with stakeholders, including the public. Invest the necessary efforts for meaningful stakeholder engagement.

Preparation is essential for success. Due to the variety and large extent of stakeholders within the health and care landscape, it is essential to dedicate the time to prepare for successful engagement, defining clear rules for co-producing IG solutions and managing the expectations.

Co-production should be used as an approach to decision-making and continual improvement based on the Scottish Approach to Service Design (SAtSD), a shared vision and assertive leadership. Co-production should be seen as a long-term habit.

Transformative public engagement models should be adopted, engaging the public in the decision-making and co-production processes, enabling interactive feedback on IG, data and digital matters, through digital and non-digital networks.

Engagement should be based on enhanced transparency from all relevant parties, including Information Asset Owners, Data Controllers, Data Processors and key IG panels, such as those for scrutinising the public benefit and the data and digital ethical dilemmas.

3 Readiness. Prepare.

Raise awareness and understanding of IG, the Scottish Approach to Service Design (SAtSD) and the ARMA model.

Due to the variety of stakeholders within the health and care landscape, and the lack of a universal definition of the Information Governance scope, it is crucial to undertake preparatory work at the early stages of the engagement strategy, as well as thought the longer term stages of the National IG Programme, to raise awareness and understanding of IG, the Scottish Approach to Service Design (SAtSD) and the ARMA model. Awareness and understanding in these specific areas, should be strengthened through training and accessible resources for stakeholders and people that need to be involved in co-producing IG solutions.

4 Inspire. Motivate.

Keep up the enthusiasm for IG improvement. Share the good news. Demonstrate benefits and results.

Many good things have happened in the IG landscape across health and care for many years. This should be recognised more frequently and used for inspiration; it is equally important to focus on areas that need improvement as it is to recognise all the good progress achieved so far.

The COVID pandemic has accelerated progress and transformation of the way health and care makes decisions over - and delivers - data and digital solutions. The professionalism and commitment of people to enable secure data and digital solutions ethically, at an unprecedented speed and complexity, should be used as a source of inspiration as it demonstrates what can be achieved, particularly when national and local efforts come together. The IG path taken as a response to COVID is a good example of how the federated IG model could work.

Innovate. Co-Produce. Scale-Up

5 People.

Empower people to be confident with IG. Empower the public through transformative public engagement and use it to nurture trust. Career pathways and CPD.

People are a key success factor for the data and digital strategies. The National IG Programme must focus on generating people's capabilities over time. This requires understanding resources capacity and capabilities in all the IG dimensions (Figure 2), empowering people to confidently play their IG role, either from the data, digital technologies, data protection, privacy, security or any other point of view.

It is essential to co-produce a revised IG Competency Framework should, aligning responsibilities and skills across the IG landscape, which should include skills and competencies for making decisions, managing, handling and using data and the associated digital technologies efficiently.

The Competency Framework should encompass all the interrelated disciplines within IG, presented in Figure 2: privacy, confidentiality, security, quality and integrity of data and related information technologies.

The Competency Framework should define key roles, core skills, career pathways and continual professional development options, and should consider the professionalisation of key IG roles in data and digital related areas, in collaboration with existing professional bodies, digital academies and other parts of the wider education system; creating a variety of pathways and alternatives that work for a diverse range of people's needs, development styles and preferences.

It is equally essential to empower the public, so they feel confident in using data and digital technologies. This should be achieved in alignment with and embedded in the existing Digital Maturity programmes of work.

Public engagement should be extensively embedded into data and digital work, from the early strategy work to delivering solutions. Transformative public engagement would allow a better understanding of the public expectations from data and digital health and care technologies and services, but also, exploration of the ethical dilemmas that may arise.

Effective transformative public engagement would nurture trust through participation and assurance.

6 Processes and structures

- De-clutter the IG landscape.
- Align the IG responsibilities and processes (the National Federated IG Model).
- A common IG implementation model to improve IG maturity, locally and nationally (ARMA).

Adopt and promote use of a common IG implementations model, such as ARMA, to assess the IG maturity at local and national level, in line with the a National Federated IG Model - overall and with respect to key IG processes. Such models offer a pragmatic approach to continually improve IG and achieve the necessary maturity of each of the key processes.

A common IG implementations model helps build a common understanding and unified implementation approach that bridges people, policy, and more across these critical IG areas and processes.

Make the IG processes and structures leaner to deliver data and digital solutions more efficiently and enhancing results and trust.

Promote a national "Once for Scotland" approach wherever possible for consistency and efficiency.

7 Tools

- Investment in the right tools for the right IG tasks and processes.
- Consider toolkits equivalent to other UK nations (e.g. NHS Digital Data Security and Protection Toolkit, NCSC Cyber Security Toolkit for Boards)
- Continue developing sector-specific IG related policy and guidelines to help with compliance.

Investment is needed in priority IG tools, including digitalisation of IG tasks and processes, management of the information risk at national and local scale, management of IG improvement, as well as tools for transformative IG engagement and co-production, transparency and training on all IG dimensions included in Figure 2. Consideration should be given to implementing an equivalent data protection toolkit to those adopted by England, Wales and Northern Ireland.

An ICO approved UK-GDPR Code of Conduct should be developed, setting the specific rules and requirements across health and care, and enhancing compliance, consistency and trust among participating bodies, thereby enabling data and systems across the ecosystem to materialise the benefits set out in the Digital Health and Care strategy. The strategy sets out how technology will support person-centred care, and help to sustain and improve services for the future.

The instruments and tools used to promote transparency should be enhanced, such as those involved in the Digital/Data Ethics Framework (including reports, privacy notices, data protection impact assessments and ethics summaries).

8 Products (data and digital assets)

Establish a central Information Assets Register and establish the ownership model for National Information Assets.

A central information assets register should be established for transparency purposes and to provide added visibility towards enhanced management of existing valuable information assets across the landscape, starting with the national information assets.

The model of accountability for National Information Assets should be revised to ensure data and digital assets at local or national level enable the best possible benefits for the population of Scotland.

A central repository of data and digital assets should promote transparency and trust with regards to how those assets are used, and boost assurance to the public and amongst health and care stakeholders.

Demonstrate success and Assurance

9 IG Maturity baseline (ARMA model and index benchmarking).

Evaluation of core IG processes and the Information Assets (data and digital) lifecycle.

Adopt and promote the use of a common IG implementations model, such as ARMA, to assess the IG maturity at local and national levels, in line with the National Federated IG Model.

A common IG implementation model helps build a common understanding and unified implementation approach that bridges people, policy, and more across these critical IG areas and processes.

Such models offer a pragmatic approach to continually improve IG and achieve the necessary maturity of each of the key processes. Assess the overall IG maturity and with respect to key IG processes at local and national levels to establish the improvement baseline.

10 Plan for improvement.

Local and national IG improvement plans.

Removing duplication, inefficiencies and defects information assets, as well as making the IG processes and structures leaner, helps to deliver more efficient data and digital solutions and to enhance results, therefore boosting people's satisfaction with the ways data and digital systems are used for health and care purposes, and the assurance that this takes place ethically and securely.

Scotland can benefit from using the ARMA IG Implementation Model to plan for improvement at local and national levels on key areas of IG maturity (leadership, people, policies, processes, tools, internal audit capabilities, data structures, and data and digital infrastructure) (Figure 5). This will require evaluating the appropriateness of IG processes around the data and digital assets lifecycle.

It is advisable to set up a common body to lead and monitor progress through local and national IG improvement plans, as well as to provide expert support and act as a centre of IG excellence. These functions could be combined with other functions as part of the wider remit of a potential National IG body, interlinking with or embedding existing expert groups expertise (e.g. cybersecurity, records management, data and intelligence and others).

11 Monitor progress and assurance.

Local and national progress. Benchmarking.
Monitor compliance, risk position and benefits to build assurance.
Provide assurance to stakeholders, including the public, for boosting trust.

IG maturity should be monitored across the health and care ecosystem; regular monitoring of progress should be carried out at local and national levels, mapping through the extended use of the ARMA IG index and benchmarking. Each stakeholder should be enabled to undertake quick self-assessments. Central resources should be allocated to collate the results from local assessments and provide a collective national view of the IG maturity across health and care for the interest of the various stakeholders accountable for digital and data, including Ministers.

Monitoring at national and local levels should expand to encompass oversight and coordinated actions on IG progress, compliance, risks and benefits arising from data and digital.

Independent assurance reviews should be reused to promote trust among stakeholders and to inform on improvement actions; other independent reviews may also be required. Examples of such reviews are those by the Network and Information Systems Regulations Auditor or via the UK-GDPR Code of Conduct Monitoring Body for Health and Care (once established).

The national and local assurance mechanisms should evolve over-time. Enhanced audit and internal control should be strengthened in the areas of privacy, data, information systems, security and resilience ("just trust me" is not enough).

Trust should be nurtured through assurance and enhanced transparency in data and digital operations and confidence in the achievement of stakeholder objectives.

12 Scale up.

Scale up IG that works well (e.g. COVID-19 lessons)

Scaling up what worked well:

a. successful models from the COVID-19 pandemic, such as the Data and Intelligence Network and the governance model of the Vaccinations Programme, should be expanded to other areas;

b. examples of good practice/guidance across the wider ecosystem should be shared with key public sector contacts, followed by monthly updates via a simple online open-access registry.
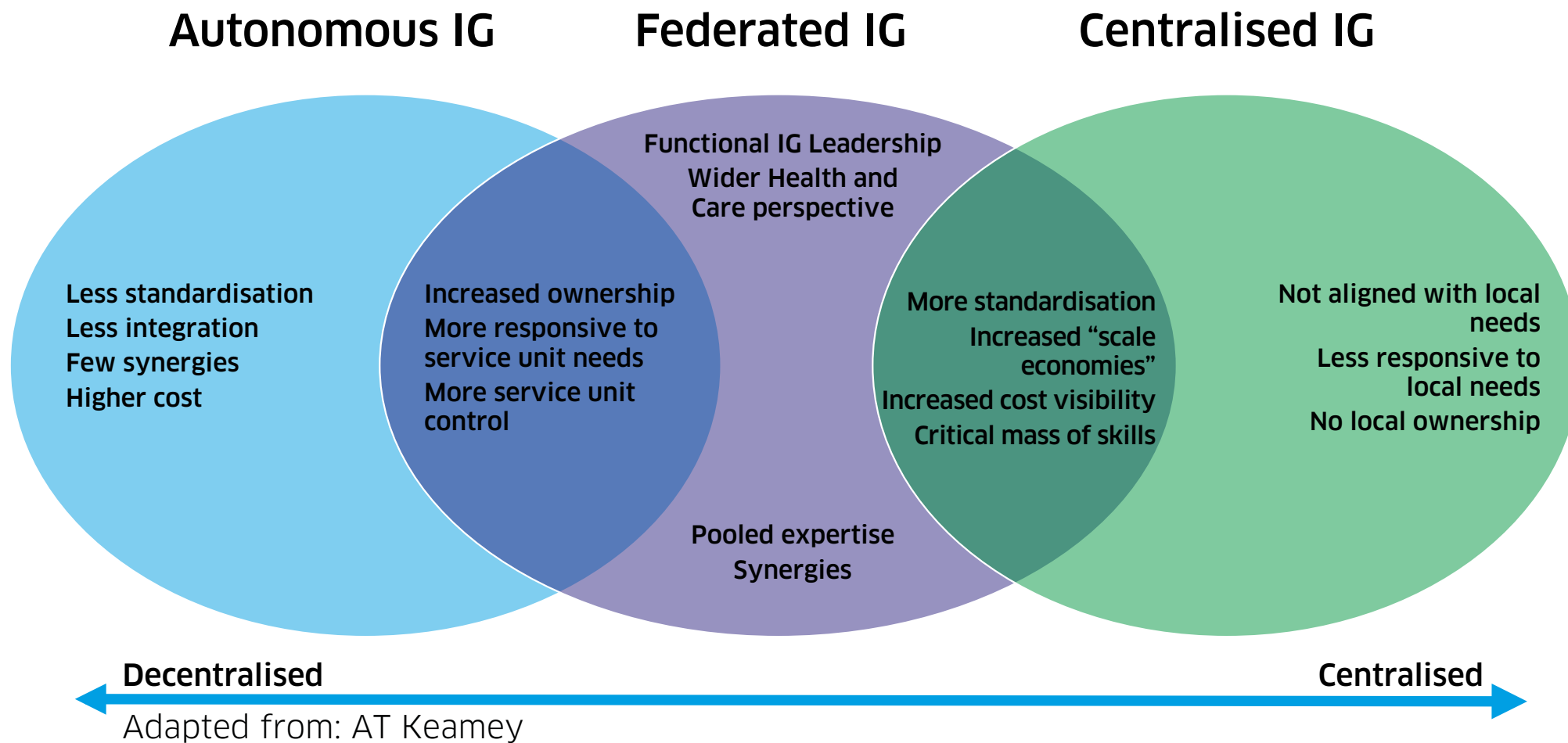
Autonomous IG

Federated IG

Centralised IG

Functional IG Leadership
Wider Health and
Care perspective

Less standardisation
Less integration
Few synergies
Higher cost

Increased ownership
More responsive to
service unit needs
More service unit
control

More standardisation
Increased "scale
economies"
Increased cost visibility
Critical mass of skills

Not aligned with local
needs
Less responsive to
local needs
No local ownership

Pooled expertise
Synergies

Decentralised

Centralised

Adapted from: AT Keamey

Figure 8. Organisational models for facilitating IG innovation

Key decision flow   COBIT 5® – Enabling Information. ISACA
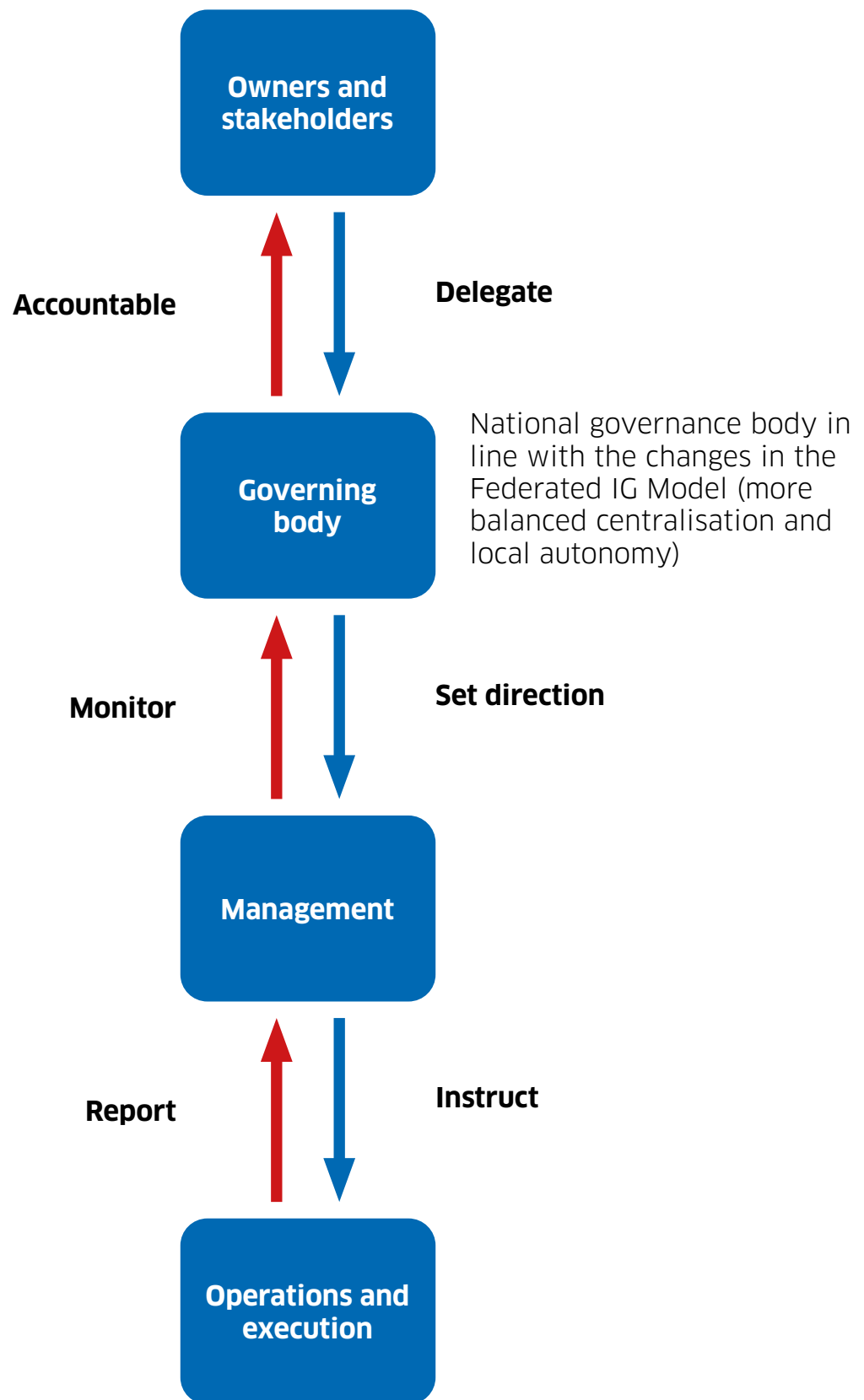
Figure 9. IG decision-making flow (ISACA)

6. What now? Next steps.

Establishing, and subsequently prioritising, the Review's key recommendations underscored the importance of establishing a set of clear, sequential and actionable next steps that are informed by the findings.

It is proposed that the National IG programme focuses efforts on the following key areas towards the National IG reform:

- A more balanced federated IG model with a National IG body
- Increase collective IG maturity (local and national) by monitoring the IG maturity across the ecosystem
- Empowering people
- Enabling IG: providing the right tools for the IG job
- Improving transparency
- Enhancing public engagement

Figure 10 illustrates the key areas of work through illustrative phases towards a successful national IG reform, that will streamline the information governance (IG) national approach, addressing inconsistencies in decisions over the use of data and digital technologies, minimising variation (data and digital systems post code lottery) and harmonising the management of the information risk collectively at the national, removing the barriers that currently obstruct the realisation of benefits from digital and data-driven health and care innovation.
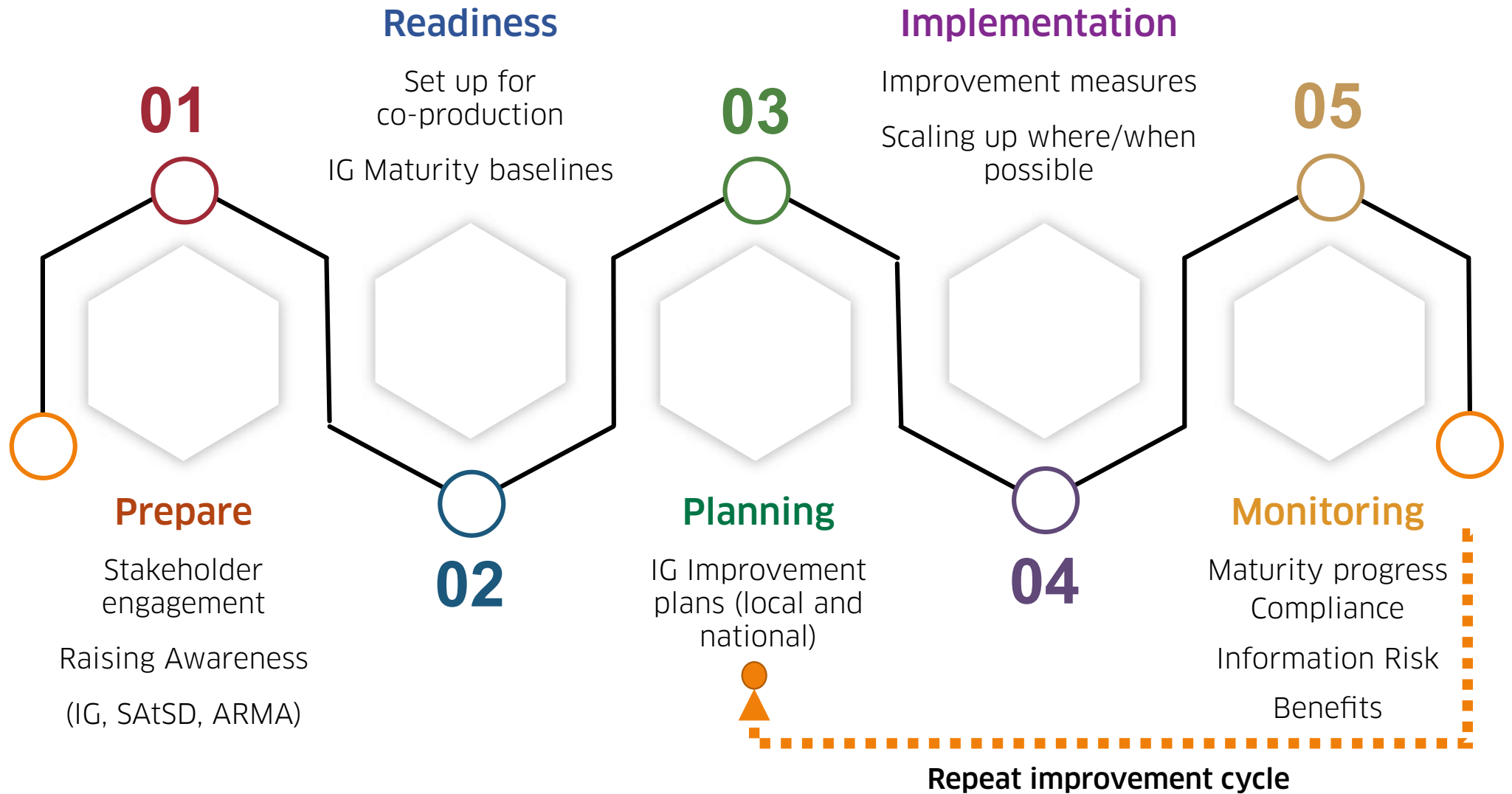
Next Steps: National IG Programme for Health and Care

Readiness

01

Set up for
co-production

IG Maturity baselines

Implementation

03

Improvement measures

Scaling up where/when
possible

05

Prepare

Stakeholder
engagement

Raising Awareness

(IG, SAtSD, ARMA)

02

Planning

IG Improvement
plans (local and
national)

04

Monitoring

Maturity progress

Compliance

Information Risk

Benefits

Repeat improvement cycle

Figure 10. The National IG Reform timeline