Cross-Party Group on Life Sciences

Tuesday 20th February 2024, 17:45 – 19:15

Minute

MSPs

Kenneth Gibson MSP
Michael Marra MSP
Graham Simpson MSP

Invited guests

Fiona Hamill, Senior Manager, Enterprise Government Affairs & Policy UK, (Johnson and Johnson
Professor George Crooks, CEO, The Digital Health and Care Innovation Centre (DHI)
William Kendall, Product Manager (DHI)
Dr David Irvine, Consultant Haematologist, Queen Elizabeth University Hospital, Glasgow
Professor Roger Halliday, CEO (Research Data Scotland)

Non-MSP Group Members

Ally Boyle, NHS Lanarkshire Non-executive Board member
Jacqueline Barry, Chief Clinical Officer at Cell and Gene Therapy Catapult
Marian McNeil, Chief Executive Officer at Precision Medicine Scotland Innovation Centre
Alexander Weir, Senior Technical Manager, Canon Medical Research
Alison Culpan, ABPI, Director Scotland
Andrew Henderson, Team Leader at Scottish Enterprise
Brenda Dooley, Founder and CEO, AXIS Consulting
Brian Forbes, Director, Government Affairs, Devolved Nations
Caleb Meath, Policy Manager, ABPI
Claire Headspeath, ABPI, Operations Manager
Damian Crombie, Regional Healthcare Manager, AstraZeneca
David Bowie, Managing Partner, Albany Business Consultants
David Chang, Professor of Surgical Oncology and Honorary Consultant Pancreatic Surgeon
Dr Annie McRobbie, Education Manager for Biology, SSERC
Dr Christian Cole, Senior Lecturer - Health Informatics, University of Dundee
Dr David Powell, Chief Scientific Officer (CSO), LifeArc
Dr Poonam Malik, Head of Investments, University of Strathclyde
Esmé Pringle, Reporter, Ettrickburn
Ewan Morrison, Director of Pharmacy at NHS National Services Scotland
Frankie Toner, Public Affairs Manager, Market Access and Public Affairs, Chiesi
George Davidson, Director Of External Affairs at GSK
Greg Stevenson, Director, Greg Stevenson Consulting Limited

Iain Chalmers, National Market Access Manager, Thornton and Ross
Imme Jones, Policy Lead – Data Driven Innovation, Scottish Government
James Squires, PhD, Head of Data and Digital Policy, ABPI
Joe Edwards, Director of UK Competitiveness and Devolved Nations, ABPI
John Macgill, Director at Ettrickburn Limited
Karen Facey, Evidence Based Health Policy Consultant, University of Edinburgh
Leigh Mair, Project & Development Manager, SRHP, University of the Highlands and Islands
Lindsay Cameron, Regional Access Manager, Daiichi Sankyo
Mark Cook, Chair, ILG
Mark Wilkinson, Director of Partnerships & Business Development, Data Lab
Nick Murray, Principal Pharmacist – New Medicines, NHS National Services Scotland
Nicola Watt, Team Leader at Scottish Enterprise
Nicolas Peyret, Health Economy Team Leader at Scottish Enterprise
Peter Mclaughlin, Head of IT, Precision Medicine Scotland
Philip Jones, Chief Scientific Advisor, BioAscent
Professor Crispin Miller, Head of Computational Biology and Bioinformatics, CRUK Scotland Institute
Professor David Littlejohn, Special Adviser To the Principal, Strathclyde University
Professor Frank Gunn-Moore, Head of School at School of Biology, University of St Andrews
Professor John Le Quesne, Mazumdar-Shaw Chair in Molecular Pathology, University of Glasgow
Professor Kenneth Baillie, Professor of Experimental Medicine, University of Edinburgh
Professor Seshadri Vasan, R&D Director, NHS Grampian
Professor Sir Mike Ferguson, Regius Professor of Life Sciences, University of Dundee
Robert Crawford, Healthcare Partnership Manager (Central & South Scotland), Thornton and Ross
Ryan Anderson, Policy Lead for Data and Intelligence - Digital Health and Care, Scottish Government
Sarah Hunt, Key Sector Manager – Life and Chemical Sciences, Skills Development Scotland
Sonja Hart, Senior Associate (Technology & Commercial), Burness and Paul
Stephen Jasperse, Site Engagement Director at IQVIA
Thorsten Forster, Scientific Director, LifeArc
Tobias Croft, Head of Innovation - Health, Scottish Government

Apologies

Ivan McKee MSP
Brian Whittle MSP

Agenda item 1

Opening, Welcome and Introductions

Convener Kenneth Gibson (KG) welcomed everyone to the first meeting of the Cross-Party Group in 2024.

Minutes of the previous meeting (14th November 2023)
The minutes of the previous meeting were accepted. There were no matters arising.

Agenda item 2

Scotland's Healthcare Data: A national asset?

Alison Culpan, ABPI

Alison Culpan shared insights from Fiona Hamill, Senior Manager, Enterprise Government Affairs & Policy UK at Johnson, and Johnson, about the work of the Life Science Industry Leadership Group (ILG) data subgroup to improve the current data position by transforming availability and accessibility to de-identified patient data.

Alison explained the subgroup had set up a working group, chaired by Fiona with support from universities, innovation bodies, industry, academics, and patients, to take forward work to explore the feasibility and aggregability among key stakeholders of the development of a standardized minimum dataset without the need to create a registry.

CAR-T was chosen to assess this hypothesis, due to its low patient numbers of only 70 and its single site status.

Alison explained that Precision Medicine Scotland and the Digital Health & Care Innovation Centre (DHI) spearheaded a proposal to Scottish Enterprise to explore the most viable option to take this forward. She said that a positive outcome could potentially spark interest in clinical R&D in Scotland and backed by real-world evidence, could allow for innovative payment models for treatments.

She said outcomes of this work have now been integrated into a larger AIM4ALL project led by DHI. She concluded by saying this is a stellar example of a unified effort to achieve the best outcomes for patients.

Professor George Crooks, CEO, The Digital Health, and Care Innovation Centre (DHI)

Professor George Crooks, CEO of The Digital Health, and Care Innovation Centre (DHI), explained that the DHI has been funded to utilise next-generation tools and services to address challenges faced by citizens and create economic advantages for Scotland. He stressed the importance of global governments planning for the impacts of workforce challenges, rising expectations of citizens, and exponentially increasing healthcare expenditure.

He explained that the Digital and Data subgroup of the Life Sciences ILG has, since June 2022, been implementing an action plan with priorities in areas including national infrastructure, enabling technologies, increased digitisation, data, AI, and innovation.

He outlined the key findings and resulting recommendations by the subgroup to drive innovation and improve efficiencies:

- Formal ministerial recognition of the importance of data, with a designated minister to champion this work.
- Development of a single national data access process to enable efficient data access for industry researchers and academics.
- Advancement of the agenda in information governance, and creation of a unique selling point for Scotland by providing clarity around the process and available data.
- Focused and granular demand signalling to maximise resource usage.
- Prioritisation of industry engagement with Scotland's data and AI assets to avoid missing significant inward investment opportunities.
- Creation of a roadmap to provide the right support to companies at the right time in their innovation journeys.
- Establishment of a working group to advance a strategic, joined-up communications plan.
- Professor Crooks mentioned that the AIM4ALL CAR-T project highlighted the issues faced with data in Scotland, with no standardised dataset and no easy way of collecting patient data, all underscoring the need for change.

He showed a video of Dr David Irvine, a consultant haematologist based in Glasgow, who emphasised the importance of availability and equitable access to advanced therapeutics, specifically CAR-T. Dr Irvine explained that these life-changing therapies are emerging with limited data, disrupting standard routes of access. He stated that Scotland is at the forefront of these innovations, but there is a need to evaluate the true value of these drugs effectively and gain access to them early. He suggested that AIM4ALL could potentially be instrumental in ensuring this.

Professor Crooks stressed the necessity for Scotland to transition to a model where data is collected once and used for all aspects across the data continuum, from medicines discovery to regulatory purposes and post-marketing surveillance. He stated that with a robust data infrastructure, where safe storage and data quality are assured, Scotland will be seen as a go-to place for R&D. He emphasised that any digital solution must address the needs of everyone in Scotland, including patients, clinicians, and data controllers. He explained that Research Data Scotland (RDS) and DHI are working to simplify the landscape and design a system to support the new ways Scotland wants to deliver care.

William Kendall, Product Manager (DHI).

William Kendall, (Bill) Product Manager at the Digital Health and Care Innovation Centre (DHI) provided an overview of the AIM4ALL proof of concept (PoC) journey. He explained that the PoC aimed to demonstrate the viability of:

- Mapping and standardising an exemplar treatment journey into formal descriptions and capturing it in a platform.
- Revising that platform to digest and manage data in the long term.
- Using the platform to securely share standardised data to meet the needs of researchers and contracts.

Bill stated that the project was completed on a 'shoestring', with examples of good practice recycled and improved to avoid the need for a novel solution. He explained that the project aimed to extend the use of an existing platform, the Health Data Exchange, which is already used in NHS Scotland for digital dermatology, COVID results, and notification service. The platform can take de-identified data from safe havens, then stage, import, store, and manage it to be ready for sharing. A simple dashboard application was built to allow authorised users to search for data. A standard space interface was also created to allow secure data sharing, including with a contract management system to allow for innovative pricing arrangements. Bill confirmed that the PoC proves the concept will be extendable to other disease types and treatments. He highlighted that development of the platform is sustainable in terms of cost and efforts, is repeatable and predictable, and has not created any laborious new tasks for NHS IT teams.

Q & A

In response to a question on plans for scaling the project, George said that AIM4ALL phase 2 will now look to create the case for embedding this into the existing ICT infrastructure in NHS Scotland. He said, for this process to be successful, it must link with key players at other parts of the data journey to ensure everyone is working in an integrated way to scale this up.

In response to a question about interoperability with NHS England, George said that this is being considered. He said conversations are ongoing with colleagues in England and in other medium-sized countries. He explained that this will be critical to building up the evidence base and to bring data from these jurisdictions together. He said using de-identified data means they are able to overcome many of the perceived barriers to this work faced by countries all over the world.

In response to a question about how this platform will interact with health technology appraisals, George said this is all about adding value to the existing system. He said

it will be important to take this forward in a meaningful way that does not destabilise existing systems but moves Scotland into the 21st century. He said conversations with academics, clinicians, and patients will all be critical to inform learning in the system and develop a data landscape that works for everyone.

In response to a question about quantifying the economic benefit of this work, George said that medium-sized and large pharmaceutical companies are saying that this type of data landscape and approach are an important consideration in R&D. He said the case for further investment will be built when this is scaled nationally.

In response to a question on why this solution has not naturally evolved within NHS Scotland, George said the pressures faced currently by NHS Scotland mean no one had the onus or means to convene people to drive change. He said the PoC was enabled by the willingness of all stakeholders to help.

Agenda item 3

Unlocking data to save time, money, and lives.
Professor Roger Halliday, CEO (Research Data Scotland)

Professor Roger Halliday spoke about the need to make a step change in data sharing and access. He explained that the problems that exist in Scotland, notably speed of access, demonstrating trustworthiness, reducing complexity, widening range of datasets, and connecting data will require input from agencies across sectors.
He said the overarching goal of RDS is to bring together and curate the excellent data available in Scotland and better connect this.
He told the group that a Researcher Access Service is due to launch soon, which will mean researchers will be able to spend much less time applying to access data. Nine datasets will be available in this first release, including PIS (prescribing information system) from 2009 onwards. In 2024/25, RDS will look to expand this to include more datasets, including those for hospital prescribing and home care prescribing, and to have a system that can deal with more complex inquiries. He also expects GP practice data to be made available by the end of the year, though Scotland wide data on genomics and from NHS laboratories will take significantly longer. He said that the full researcher access service is due to be in place by spring 2025.
Roger told the meeting that an industry data access operational policy is currently being developed. He said RDS is eager that this aligns with Scottish Government policy and that decision making over data access is likely to be based upon public good.

Roger spoke about the cohort discovery tool, which is being developed in collaboration with Health Data Research UK, Public Health Scotland, and the University of Dundee. He said this will enable researchers to search for people based on a specific condition or demographic. He said the aim is to have the first iteration of this tested and available later this year.
He concluded with highlighting that access to data is key and that Research Data Scotland is committed to addressing some of the central issues with the data infrastructure.

Q&A
In response to a question about the charitable status and reporting governance of RDS, Roger explained that RDS is a charity owned collectively by the Scottish Government, Public Health Scotland, and the universities of Aberdeen, Glasgow, and Edinburgh. RDS reports to a board of representatives made up of these organisations. A range of organisations fund RDS, including the Scottish Government. He highlighted that there is not a clear single minister that RDS reports to, though it has typically been Minister for Small Business, Innovation and Tourism, Richard Lochhead, and Shona Robison as Deputy First Minister.
In response to a question on how the organisation determines the 'public good' of studies, Roger explained RDS works to a standard, independent definition of the public good from the UK Statistics Authority. He said it depends on the level of perceived risk or complexity of a project whether assurance is sought from a public panel.
In response to a question about competing efforts in leading data transformation, Roger explained RDS is well connected and networked in Scotland and is being looked to provide that leadership.
In response to a question about efforts to standardise this across the UK, Roger said RDS is cognizant of the need to align. He explained RDS works closely with HDR UK to develop standards. He also outlined a memorandum of understanding of joint work with the SAIL databank in Wales, and RDS is working with the equivalent body in Northern Ireland and the Office for National Statistics on approaches to connect data across the UK.
In response to a question about international funding, Roger said it will be important to focus for the time being on getting things right in Scotland.

Close
Kenneth Gibson concluded the meeting.

The next meeting of the CPG on Life Sciences will take place on Tuesday the 21st of May 2024.