Scottish Parliament Cross Party Group on Cancer

Wednesday 24th February 2016, 17.30-19.00

Minutes

Attendees and apologies noted in appendices. **Bold underlined text indicates actions/ agreements**

1) Welcome

Malcolm Chisholm MSP ("the Chair") opened the meeting, welcoming all attendees and speakers.

2) The Draft Minutes from the last meeting were approved

3) The Chair welcomed Dr Aileen Keel (AK), Director, Innovative Healthcare Delivery Programme (IHDP) to speak on Modernising Scotland's cancer data and intelligence

AK began by highlighting that she has been seconded for three years from the Scottish Government into the role. She outlined the role of the IHDP, stating that it aims to link primary, secondary and social data with a view to ultimately improving cancer outcomes. She noted that until we can join up the data and utilise it better, we can only speculate with regards to cancer data and the underlying drivers impacting incidence and mortality.

This project will help benchmark Scotland both against the rest of the UK and internationally, with continuous qualitative improvement a key measure of success.

AK noted we need to get much better in Scotland at releasing data in near-real time. She confirmed that England currently has a much richer system of data capture and analysis than Scotland. They are able to use near real-time data (data that is only three months in arrears) as opposed to the 18-month wait for data that currently applied in Scotland. By that time, it is almost out of date and the picture has moved on.

Scotland also doesn't afford cancer patients access to their own data, AK noted. She confirmed however that research shows patients do want their information to be shared, albeit confidentially, and are actually surprised in her experience to learn that more isn't currently being done with their data.

AK talked through some of the key barriers to change. She identified the quantity of different datasets as a key barrier – as well as the paper-based, rather than online, nature of some of this data. The IHDP team did a tour of Scotland's five cancer centres, to talk about the project's vision and the barriers that exist. One of the themes that came across strongly from this was that the rules around information governance are applied differently across Scotland, and that a standardised approach is needed.

As a result, the IHDP will be setting up an Information Governance Sub-Group.

AK stated she believes the technological and information governance barrier are surmountable. She pointed towards diabetes and renal, where data is currently used effectively.

4) Questions to AK

Questions were taken from the floor, and discussion was wide-ranging. On the subject of Patient and Public Involvement (PPI) and third sector involvement, AK confirmed that the IHDP is looking to have two patients on the Information Governance sub-group, and would welcome third sector presence too. Timings of the project were discussed, with AK stating that her aim is to have a similar system to that in England in place by the end of her three year secondment. The extraction of primary care data was touched on, with AK confirming that cancer is the top of the list of data that needs to be extracted, and indeed that some data is already being collated by the International Cancer Benchmarking Partnership (ICBP). Asked about how better quality data could impact on the decisions of the Scottish Medicines Consortium, AK suggested that data regarding the effectiveness of SMC approved drugs could be fed back in to the SMC, providing real-world evidence to help inform its decisions. Specific questions were also asked about pancreatic and bowel cancer detection at the primary care level and the availability of related data.

5) The Chair then welcomed Professor David Cameron (DC), Scottish Government Cancer Research Champion to speak on the Scottish cancer research environment and its challenges

DC began by differentiating two different types of research streams in the NHS: (1) academic funding, supplied by the Scottish Government, the UK Government, and charities, and (2) the commercial stream, which consists of research into the development of novel drugs and technologies, usually paid for by a commercial sponsor. Across both pathways, he noted that the concept of running research in a structured network approach is embedded in Scotland.

The far-reaching benefits of research were outlined by DC: hospitals that do more clinical research achieve better outcomes for all patients in that disease area, he argued – not just the patients involved in the study.

On patient expectations, DC noted that patients are increasingly expecting to be offered access to a clinical trial, and that they must be part of the driving force to do more research.

DC then turned to trail recruitment numbers. The UK recruits a higher proportion of cancer patients into studies that any other country – four times as much as the USA. Yet while Scotland has traditionally punched above its weight in terms of recruitment into trials, compared to England, that is no longer the case.

That is partly down to changes to the type of research that's being conducted, DC suggested, and the introduction of more niche studies – thus finding the right patients gets harder. The median sample size of a trial has fallen to $1/6^{th}$ of its previous size. That means six times as many trials are needed to recruit the same number of patients.

DC also explored the theme of precision medicine, and its impact on trial sizes. Because clinicians are harnessing biological tools and increasingly using precision medicine to check if a patient is eligible for the study in the first place, recruiting the right patients for the right trials is harder.

Other challenging areas DC raised with regards to recruitment into trails include teens – whose recruitment rates into trials is lower than that of children – older patients, and remote populations.

NHS challenges meanwhile stem largely from tighter resources due to an ageing population. DC stressed the need to ensure that the budget for R&D gets spent on R&D, and doesn't end up propping up struggling services. We must maintain a culture that considers research part of the NHS' core business, he argued.

DC's summing up remarks noted that clinical research is not getting easier, and better cohesion is needed across Scotland. More thought needs to go into access to trials, he suggested, than the overall number of patients involved in trials.

6) Questions to DC

The chair opened the discussion to the floor, with key themes of questioning including the economics and logistics of trials in Scotland, the ownership of trial initiation, and how clinical time for clinical research can be better safeguarded. DC argued that research time should be embedded into the core NHS service, so that is service pressure rises, it is still recognised that research is integral. Asked about the impact of the EU Clinical Trials Directive, DC expressed the view that even if the UK leaves the EU the bureaucracy surrounding clinical trials would not change.

7) A.O.B.

Noting that both Malcolm Chisholm MSP and Nanette Milne MSP are both standing down at the forthcoming election, the secretariat thanked the co-convenors for their support and input over the course of their tenure.

The Chair then closed the meeting.

The date of the next meeting will be confirmed after the Scottish Parliament election on the 5th May. Members will be kept informed via the secretariat.

Attendees

Colette	Backwell	CLAN Cancer Support
Lorna	Bruce	SCAN
David	Cameron	University of Edinburgh/ NHS Lothian
Malcolm	Chisholm	MSP
Lawrence	Cowan	Breast Cancer Now
Jeannie	Erskine	Patient
Jennifer	Fingland	SHAAP
Heather	Goodare	Edinburgh Health Forum
Roseann	Haig	Circle of Comfort
Peter	Hastie	Macmillan
Debbi	Jennings	Beatson Cancer Charity
Aileen	Keel	Scottish Government
Gregor	McNie	Cancer Research UK
Nanette	Milne	MSP

Francis	Norton	Heads Up Cancer Support
Liz	Porterfield	Scottish Government
Ewan	Shannon	
Leigh	Smith	MASScot
Suzanne	Spencer	Cancer Research UK Ambassador
Greg	Stevenson	Roche
Mona	Vaghefian	Cancer Research UK
David	Welch	Beatson Cancer Charity
David	Weller	University of Edinburgh
Norman	Wilson	Pancreatic Cancer Scotland
Keri	Wyatt	Bloodwise

Apologies

Ellen	Finlayson	Clic Sargent
John	Sleith	Royal Environmental Health Institute of Scotland
Kaz	Molloy	Womb Cancer Support UK
Lynne	Barty	Brain Tumour Action
Mary	Dunlop	Cancer Research UK
Alan	Rodger	
Michael	Clancy	Law Society of Scotland
Alison	McInnes	MSP
Ali	Walker	South of Scotland Cancer Network
Colin	Selby	South of Scotland Cancer Network
Elizabeth	Preston	NHS Lothian
Emilia	Crighton	NHS Greater Glasgow & Clyde
Hakim	Benyounes	NHS Lanarkshire
Ian	Campbell	NHS
Lindsay	Campbell	West of Scotland Cancer Network
Marie	Mathers	NHS Lothian
Mark	Parsons	Macmillan Regional Cancer Pharmacist
Mhairi	Simpson	NHS Lanarkshire
Murdina	MacDonald	NHS Fife
Peter	Hutchison	Scottish Primary Care Cancer Group
Sheena	Dryden	NHS Lothian
Val	Doherty	South of Scotland Cancer Network
Kim	Rowan	Cancer Patient
Peter	Phillips	South of Scotland Cancer Network
Katie	Robb	Institute of Health and Wellbeing
Marie	Gardiner	NHS Lothian
Mil	Vukovic Smart	Leukaemia & Lymphoma Research
Gillian	Philips	Cancer Research UK
Andrew	Dempsey	Celgene
Jo	Williamson	Cancer Research UK Ambassador