Healthcare Priorities and Societal Values: The Current Position

Seminar Report

The Academy of Government, Healthcare Improvement Scotland and the School of Social and Political Science jointly organised a seminar that took place on 15th November 2017 in Edinburgh.

The seminar was held under the ‘Chatham House Rule’ which says:

*When a meeting, or part thereof, is held under the Chatham House Rule, participants are free to use the information received, but neither the identity nor the affiliation of the speaker(s), nor that of any other participant, may be revealed.*

30 people participated in the seminar, comprising civil servants, academics, researchers, third sector, and NHS and Social Care professionals. In keeping with the Chatham House Rule, comments by particular individuals have not been identified in the report, but the Chair and Seminar Speakers have consented to be identified.

The seminar was the first of two seminars to explore how we currently approach prioritisation issues in Scotland, what challenges we face, and how we may wish to plan for the future. The first one looked at:

- Current approaches to priority setting in Scotland including the ‘Making Difficult Decisions’ Framework
- Practice around the world in engaging in transparent and public attempts to set healthcare priorities
- Recent case studies from Scotland including homeopathy and IVF treatment

Background to the issue

The allocation of scarce care resource raises ethical issues and is frequently at the centre of political controversy. Across the world, healthcare systems are increasingly recognising the need for public engagement and transparency of systems and decisions impacting on the distribution of care resource, particularly as new developments in medicines and other care technologies create ever greater financial pressures on stretched services.

‘In Scotland, the Scottish Health Technologies Group, Scottish Medicines Consortium and SIGN (Scottish Intercollegiate Guidelines Network) use evidence to inform local technology adoption and prioritisation decisions by assessing the relative clinical and cost effectiveness of care technologies. Many other factors and decision processes impact on the allocation of care resources and are typically less explicit or transparent. How do we account for these and how do we include societal values in recognition of the ethical and societal dimensions involved?'
The ‘Montgomery Review’ of Scottish Medicines Consortium processes reported in December 2016 that:

“Any framework has to develop an accepted model of value that is sophisticated enough to deal in multiple currencies of which money is only one. Discussions in this Review moved between cost, cost-effectiveness, affordability and value accepting that they are all different but inter-related. The most challenging to define is value and in a Scottish Model of Value it will be important to ensure that it is measured and expressed in broad but consistent terms. These terms cannot be confined to clinical effectiveness and medical outcomes but need to take account of personal considerations and wider societal factors. The metrics need to be applicable not just to this small group of medicines but to an array of treatments and interventions in a way that informs and supports meaningful comparisons and difficult choices.”

The report also commented that there was concern that “medicines were not being treated equitably when compared with other healthcare treatments and technologies.”

There is much interest around the world in approaches to elicit and incorporate societal preferences in the prioritisation of resource available for care. Some will be familiar with the ‘Oregon Experience’ from 1989 onwards which engaged with the public on issues of prioritisation. Other approaches have been tried since then in different healthcare systems.

The seminar was chaired by Professor Andrew Thompson, Chair of Citizenship and Public Policy at the University of Edinburgh who welcomed everyone and explained the purpose of the seminar.

**Arguments for and against explicit priority setting and international approaches**

*The first presentation by Richard Norris, Visiting Fellow at the Academy Government, looked at the history of finding solutions that involve a public focus, including a study that looked at eight countries and compared their processes.*

Although terms like ‘priority setting’ and ‘rationing’ are sometimes used interchangeably, they can also be used in quite specific ways to mean setting priorities at the population level (priority setting) and the effect of those decisions on individuals (rationing). ‘Rationing’ is a term that is quite controversial, and in particular has lots of political sensitivities attached to it, and does not tend to be used in political debate.

Rationing can be seen as explicit or implicit, and one definition makes this distinction as follows:

‘Explicit rationing’ refers to decisions made by an administrative authority as to the amounts and types of resources to be made available, eligible populations, and specific rules for allocation.

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1 Review of Access to New Medicines. Independent review by Dr Brian Montgomery. Scottish Government 2016. 6.12.4
2 Ibid 2.9
‘Implicit rationing’, in contrast, refers to discretionary decisions made by managers, professionals, and other health personnel functioning within a fixed budgetary allowance.\textsuperscript{3}

The NHS is seen as a system that exemplifies implicit rationing. Rationing is ‘messy’ and people ‘muddle through’, but sometimes this leads to trade-offs, or decisions by default, that may not be seen as fair or evidence based. Sometimes it is felt that the lack of an explicit approach reinforces the view that the NHS is expected to ‘do everything’ when in practice it is always having to make decisions about what it can provide.

Current approaches to healthcare prioritisation in Scotland

- National priorities e.g. Health and Wellbeing Outcomes
- Regional Planning / Strategic Planning/ Local Delivery Plans
- Guidance and standards
- Targets and Indicators
- Government review bodies (e.g. IVF)
- Waiting lists
- Cost and clinical effectiveness assessments
- Organ allocation for transplant
- Service Change (e.g. hospital closure, types of treatment)
- Implicit rationing (e.g. decisions not to do things, or decisions to reduce availability or geographic access)
- ‘bedside rationing’
- Rationing by ‘dilution’
- Making Difficult Decisions framework

On the same day as this seminar (15\textsuperscript{th} Nov 2017), Sir Harry Burns’ review of targets and indicators was published which stated ‘A target is a way of expressing the priority of an organisation.’\textsuperscript{4}

Avoidance is also a form of prioritisation e.g. avoidance of developing service change proposals or carrying them through.

‘Rationing by dilution’ is where the same services continue to be offered, but there are fewer staff on the ward or in the practice, the quality of hospital food reduces, there are less diagnostic tests, waiting times lengthen, and the overall quality of care and treatment declines.

Not all priority setting, or rationing, is due to limitation of funds. Organ allocation for example, is limited by availability of donors.

\textsuperscript{3} Mechanic D. Muddling through elegantly: Finding the proper balance in rationing. Health Affairs 1997

\textsuperscript{4} Targets and Indicators in Health and Social Care in Scotland. A Review Prof. Sir Harry Burns. Scottish Government 2017
We know very little about ‘bedside rationing’ – which is the effects of decisions by clinicians determining who gets what. International studies have found that most strategies employed by doctors were implicit, but factors influencing their decisions included a patient’s age (those over 85 were less likely to be referred for tests), the patient’s ability to exercise pressure, and their perceived relative ‘contribution’ to society. In other words international studies have found that implicit rationing can discriminate against people on grounds of age, employment status, or those who are less assertive.

Recently there have been a number of public calls from professionals and politicians for a more explicit approach in Scotland to deciding what the NHS delivers, and the importance of involving the public in that discussion.

However a number of arguments have been made over the years against explicit rationing. These include:

- Explicit rationing is inflexible in responding to the contingencies of people’s real lives, i.e. the fact that we need to respect that patients have different needs, values and preferences and this is best done with implicit rationing
- Explicit rationing brings into a public forum conflicting needs and preferences, resulting in acrimony and political mobilisation and is therefore susceptible to political manipulation
- Disaffected people will continue challenging either the rules of allocation or decisions, leading to further frustration and a diminution of public trust in the system
- Waiting lists are seen as less contentious than absolute prohibitions on treatments
- In practice it is impossible to carry out explicit rationing fairly or well: “There is no such thing as a correct set of priorities, or even a correct way of setting priorities.”
- A plurality of conflicting values exist in relation to healthcare and this makes it both undesirable and foolish to search for an over-riding set of principles
- ‘Deprivation disutility’ i.e. knowing that something could have been done, but was not, can be the cause of additional pain and suffering

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5 These first four bullet points taken from Mechanic D. “Muddling through elegantly: Finding the Proper Balance in Rationing” 1997
However, there are also a number of arguments that have been made in favour of explicit rationing:

- The NHS was founded on the principle that there should be equal access to health care within the NHS based on equal need – ethical issues are therefore at the heart of the NHS and are already explicit (even if approaches to rationing are not)
- Attempts to clarify moral principles for rationing are not doomed to failure. We must have the moral courage to develop them further to ensure that they form the explicit basis for rationing decisions at both micro and macro levels
- The argument for implicit macro rationing on the grounds of preserving bureaucratic and political stability is just unrealistic
- Superior technical competence does not give physicians a superior moral competence for placing relative values on human lives (a point often made by clinicians themselves)
- The continuing problem of health inequalities demonstrates current approaches are not working
- Modern expectations of openness and the demonstration of fairness in the distribution of public goods require resource allocation to be explicitly justified

One academic, David Mechanic, has argued for an approach he calls ‘Muddling Through Elegantly’, which combines elements of both implicit and explicit rationing. In this approach, explicit decisions are made in establishing the overall amount of resources allocated for health and care, and explicit formulas are developed to achieve equitable distribution of resources among health personnel and facilities, new technologies, and research. Explicit decisions are also made about extremely expensive interventions that benefit few persons. However, it is not possible to micro-manage the care process, to make explicit and bureaucratic decisions about who should be treated and how, and therefore these ‘point of care’ decisions should largely remain implicit. Doctors and patients should be allowed to challenge decisions using dispute mechanisms and a structure of procedural justice.

He argues that there is wide public acceptance that decision making at the micro level should remain implicit, but the fairness of the overall approach needs to be demonstrated otherwise the process becomes unstable because it loses political legitimacy.

A 2008 international study looked at eight countries/regions, all of whom had attempted explicit priority setting, and compared the results. It was found that there were fundamentally two approaches: the ‘outlining principles’ approach and the ‘defining practices’ approach.

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9 First 3 points taken from Doyal L. Rationing within the NHS should be explicit: The Case For. British Medical Journal 1997
10 These points taken from D. Mechanic: Muddling through elegantly  1997, and Rationing of Health Care 2015
The ‘outlining principles’ approach has been used in Norway, Netherlands, Sweden and Denmark, and develops principles that can be used for making prioritisation decisions. The principles are typically developed by a specially established Commission or Council (e.g. the Danish Council on Ethics). However it has proved difficult to demonstrate impact on policy for principles generated this way, as often the principles themselves and the guidelines generated were very high level and did little in practice to resolve questions of choice in individual circumstances, and controversial issues were often avoided.

Comparisons across eight countries
Norway, Sweden, Netherlands, Denmark

The ‘outlining principles’ approach: developing principles that would guide prioritisation efforts

- Norway – 1987 Commission approach – used severity of condition as sole basis for prioritisation. Ten years later a second commission wanted severity to be balanced with potential effect and cost effectiveness.
- Netherlands – Committee on Choices in Health Care 1990. 4 priority principles: necessity, effectiveness, efficiency and individual responsibility
- Sweden, Parliamentary Priorities Commission 1992, 3 platform principles: human dignity, need and solidarity, and cost-efficiency
- Denmark: 1996 Danish Council on Ethics – 4 principles: equality, solidarity, security and autonomy

Study by Sabik and Lie, ‘Priority setting in health care: Lessons from the experiences of eight countries. 2008

The alternative approach is the ‘defining practices’ approach, which is to establish bodies that would make practical recommendations about what services or treatments should be provided in the system. This approach was adopted by the UK, Israel, New Zealand and the State of Oregon in the USA. All these countries, with the exception of the UK, started by trying to establish some set of principles, but the focus was on making concrete allocation decisions.

Comparisons across eight countries ...

Oregon, New Zealand, Israel, United Kingdom

- The ‘defining practices’ approach – rather than beginning with abstract principles, confront priority setting in the context of concrete allocation decisions
  - Oregon: early example of explicit priority setting. Extend coverage by limiting coverage incorporating public values
  - New Zealand: 1993 National Advisory Committee to identify discrepancies in provision, opportunities for efficiency and preferences of communities
  - Israel 1995 Basic basket of services, with assessment of new technologies
  - United Kingdom: NICE 1999 (but also SIGN 1993, Clinical Standards Board for Scotland 1999, Health Technologies Board for Scotland 2000 ....)
The study found that those using this approach were:

- more likely to be able to demonstrate impact on policy and practice,
- that the process did produce specific recommendations,
- but there was a bias towards reviewing new technologies\textsuperscript{12}.

For both types of approaches the study concluded that the processes tended to be expert-driven, and not particularly open or transparent and with limited public discussion of trade-offs, and that explicit approaches had not led to changes in practice or savings. This latter point has been called the ‘political paradox of rationing’, which is that the more public a decision making process is about priority setting or rationing, the harder it is to make decisions that control costs.

The conclusions from this presentation were that:

- It is not a case of choosing between explicit or implicit rationing/prioritisation, but how to get the right balance
- There also needs to be a balance between cost effectiveness and fairness
- It is difficult to fairly compare different patient groups or community needs
- The rising costs of some treatments require savings in other parts of the system, and there is a problem of transparency over these decisions
- It is important for any system of allocation to be seen as legitimate by the public – i.e. even if decisions are made by experts societal values of fairness must be incorporated
- Involving the public is important but difficult to do well

**The Making Difficult Decisions Report**

*The seminar then heard a presentation from Dr Sara Davies, Consultant in Public Health Medicine, Scottish Government, and Dr Graham Mackenzie, Consultant in Public Health, NHS Lothian, about the ‘Making Difficult Decisions Report’ that was produced in 2010\textsuperscript{13}.*

A range of people took part in this work, from technology assessment, public health, planning, clinical and academic backgrounds.

At the time there were various organisations that had been set up to look at particular areas e.g. the Scottish Medicines Consortium in 2002, the Scottish Health Technologies Group in

\textsuperscript{12} There are behavioural theories as to why this is - losses loom larger than gains. In practice it is very difficult to disinvest in something once it is already funded, so it would be very difficult to review existing technologies (unless evidence changes e.g. long-term safety implications arise)

\textsuperscript{13} Making Difficult Decisions in NHS Boards in Scotland. 2010
http://www.healthcareimprovementscotland.org/previous_resources/policy_and_strategy/making_difficult_decisions_in.aspx
2006\textsuperscript{14}, and SIGN (the Scottish Intercollegiate Guidelines Network) had been going since 1993. However there were major planning issues, new treatments were expensive (and often only benefited small numbers), and there was concern about rising costs. It was also felt that individual decision making was leading to too much variation.

Dr Gina Radford (who chaired the Group) had helped in setting up in NICE and had moved to Scotland, and there was growing interest in how to engage in more explicit priority setting approaches here. A number of people took part in a workshop and the output was written up as a report. There were strongly different views, particularly between the view that it was important to demonstrate due process, and the opposite view that this approach was timid and was hiding behind proceduralism.

The point was made that there is growing recognition that the NHS is “mutual” in that while we often think of patients’ rights and staff responsibilities, it should be noted that patients have responsibilities too.

The ‘Making Difficult Decisions’ Framework paraphrases Daniels and Sabin’s work on ‘Accountability for Reasonableness’\textsuperscript{15} and updates it to modern language and thinks about how to apply it Scotland. It doesn’t tell you how to make the decisions.

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\textbf{Accountability for Reasonableness} (after Daniels & Sabin) \\
\hline
\textit{Publicity condition}: the public should be able to access information about decisions, and the reasons for these decisions \\
\hline
\textit{Relevance condition}: the reasons for decisions must be based on evidence, reasons and principles that all fair-minded parties can agree are relevant to deciding how to meet the diverse needs of a population \\
\hline
\textit{Appeals condition}: there is a mechanism to challenge and dispute decisions, including the opportunity to revise decisions in the light of further evidence or arguments \\
\hline
\textit{Enforcement condition}: there is either voluntary or public regulation of the process to ensure that the first three conditions are met \\
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The intention was that the framework should primarily be for NHS Boards but should be applicable to other healthcare organisations, and that the approach should be able to demonstrate a decision making process that is reasonable, transparent, procedurally fair and accountable.

\textsuperscript{14} Although the evaluation of health technologies was undertaken in Scotland prior to 2006 by the Health Technology Board for Scotland (HTBS), which was set up in 2000.

\textsuperscript{15} Daniels N. Accountability for reasonableness: establishing a fair process for priority setting is easier than agreeing on principles. BMJ 2000;321:1300-1
Firstly it was important to understand the criteria that should trigger the decision making process and ask:

- For planning/prioritisation - is this a new service development?
- For an individual treatment?
- Does the NHS Board have a policy on the issue that has arisen?
- If there is a policy, is the patient significantly different to other patients or likely to be?

The NHS Highland and Tavistock frameworks were reviewed. The principles/values in these frameworks can be broken down as follows:

- Procedural (e.g. transparency/ accountability)
- Scientific (e.g. clinical/ cost effectiveness)
- Social/cultural (links to equality/ diversity)

The group adapted the approaches taken previously, taking into account public expectations of the NHS and an up to date understanding of patient focus/public involvement to produce a coherent framework for making difficult decisions.

The result was the Making Difficult Decisions Report which recommended a process based on:

- The importance of establishing a clear timetable
- The responsibilities of decision makers
- Clear criteria to trigger process
- Sound evidence base
- Values/principles
- Justification and responsibilities
- Accepting reasonable disagreement

An example of how this was intended to work in practice was in terms of IVF (In vitro fertilisation). A clinician described how he would get roughly one letter a week, from a patient, clinician or MSP asking for IVF treatment. As an individual they did not feel comfortable making these decisions. So a local, multi-disciplinary panel was created, using the difficult decisions approach. This resulted in a dramatic reduction in waiting times, which had been four years. Sometimes it wasn’t a difficult decision, but illustrated the need for a national policy rather than making decisions on an individual basis.

Using the process has helped and in fact the Difficult Decisions Board has now folded due to lack of referrals, as decisions were being made ‘2 or 3 rungs down’.

Since the Making Difficult Decisions report in 2010 there have been new developments including CEL 17 (2010) on new medicines, the 2020 Strategic Vision and Narrative, ‘Making

One question asked was whether the Scottish Government is too NHS-centric in its provision of health services? This is more relevant given the Scottish Government is increasingly becoming a delivery organisation for well-being beyond the NHS as benefits/social security services are devolved. There is more separation in England (e.g. local authority responsibility for public health) and can we learn from that?

There was a discussion about the difficulties of spreading best practice in relation to Making Difficult Decisions. It has been found difficulty ‘spreading things’ from one service to another.

One of the strengths and limitations of the Making Difficult Decisions Framework is that it doesn’t have much content, i.e. it doesn’t tell you how to make the decisions. You need to consult with clinicians and public. So for example IVF decisions will be quite different from cardio-thoracic decisions. This also creates difficulties in spreading practice.

It was felt that if we can’t succeed in one small and very fraught area that the public cares about, is there any hope at all of generalising any form of difficult decision making?

One of the big challenges is how we can generalise? Quite often the specific details are important.

It was noted that public involvement in the process of developing the framework was limited, with someone from a consumer organisation involved, but no wider public input. There is now more interest in ‘deliberative approaches’ (e.g. Citizens Juries) and we will hear more about them in the next seminar.

Participatory budgeting was also mentioned, for example in Brazil, where ‘huge swathes’ of people have been involved, and this has been seen as a transfer of power, particularly as it focussed on deprived areas and linked with a drive to reduce inequalities.

However people also noted challenges with Participatory Budgeting. Some experiences in Scotland have not been so positive. Feedback from communities is that it is difficult to shift spending from the loudest voices. People find it easy to say we want more money on this, but where are the cuts? There needs to be more focus on priority decisions rather than spending decisions.

There was recognition that the procedural framework adopted by the Making Difficult Decisions Report was helpful but it doesn’t tell you what to do exactly. The focus on values

\textsuperscript{16}http://www.healthcareimprovementscotland.org/our_work/technologies_and_medicines/shtg_ad_hoc/macswise_report.aspx
\textsuperscript{17}https://www.scotphn.net/wp-content/uploads/2015/11/Priority-setting-in-Health-and-Social-Care-Partnerships.pdf
was helpful, as people need to be shown respect. It makes the point that Making Difficult Decisions is not just about the technology, it is about other values.

There was a reference to the distinction made at the beginning of the session between priority setting at national level and ‘rationing’ at the individual level. At the national level it was felt that if we are going to consider social values in a way that is less than explicit, as opposed to just looking at the evidence on benefit versus cost, we are no longer going to be focusing on maximising the population health benefit for taxpayers from the available funding. Instead we would be putting in social values that potentially create inequality. We need to be more aware of equalities when priority setting.

It was felt that some Local Authorities have engaged very well with communities over difficult decisions, but trust needs to be built over decades for local discussions. There were different views over whether Local Authorities were better at having these discussions with local communities than the NHS.

One point made was that there is a difference in culture, because there is no expectation of co-payment in health, but there is in social care. This meant in turn there is more acceptance of rationing in social care.

There was also a feeling that sometimes Health and Social Care staff find it easier to ‘hide behind procedure’ rather than engage in ‘upfront’ discussion around difficult decisions. Talking to patients can help provide resolve issues, but the most vocal patients tend to be lawyers!

**Case study - homeopathy**

*The seminar then heard a presentation from Dr Harpreet Kohli, formerly Director of Public Health Medicine at NHS Lanarkshire.*

In 2010 a UK parliamentary review of homeopathy (by the House of Commons Science and Technology Committee) had recommended that the NHS should stop funding homeopathy. As a result of a Board clinical review there was a recommendation that the provision of homeopathy should be reviewed, and a Homeopathy Review Group was set up, with representation from public partners, staff groups, and clinicians.

The Board referred patients to the Centre for Integrative Care, which offers a range of therapies, with 80% of patients receiving therapies that include homeopathy. Most of the referrals from the Board were from local GPs. The estimated cost of £190k was not large considering the overall NHS Board budget, but it was impossible to identify precise costs, because of a global service level agreement, and the figure was probably larger.
The Review described the service and reviewed the evidence. It included a survey of patients’ views of whom 87% said the treatment made them better. There was also a survey of GPs, and although the response rate was fairly low (just over 15%) of these 33% felt Homeopathy was of value to patients. However a synthesis of evidence concluded there was insufficient medical evidence to support continued referrals to the Centre for Integrative Care. The Board decided to do wider engagement.

A Consultation report asked the public whether the Board should support referrals to the Centre for Integrative Care. The Scottish Government decided it was not major service change, and therefore the decision was for the NHS Board.

There were 6,000 responses to an online survey. 80% of the responses were in favour of continuing referrals, but 75% of responders were not resident in the Board area.

It had been agreed that the Stakeholder Reference Group would not make recommendations as such and the decision should be made by the Board of Governance. There were intense discussions at the Board Meeting, and it was not an easy decision. A vote was recorded. The Board noted the overwhelming popularity of homeopathy but also noted the lack of evidence. The question was asked: “why should homeopathy be any different from any other service we were evaluating”. A decision to cease referrals to the Centre for Integrative Care was made from April 2015. It was agreed that existing courses of treatments would continue.

The matter was discussed at the Scottish Government Public Petitions Committee a couple of months later. Another Board had ceased referrals to the Centre for Integrative Care without any public consultation but were not criticised, whereas the Board which did carry out a consultation process was ‘castigated’. The point was made that a consultation was not a decision, and that popularity was not the same as effectiveness, otherwise why have assessment bodies such as the Scottish Medicines Consortium, Scottish Health Technologies Group, National Institute for Health and Care Excellence (NICE) etc? The Board had a duty to achieve best value.

A reference was made to the Scottish Government quality dimensions– safe, effective, and person centred, and the issue about how you weight the criteria. The Board didn’t attempt that (considering it is difficult to weigh the criteria when these elements are in conflict), but made a judgement.

There was also the question of what ‘person centred’ as a concept means in the context of public health. Should this be ‘population centred’ rather than ‘person-centred’?

“There were 6,000 responses to an online survey. 80% of the responses were in favour of continuing referrals, but 75% of responders were not resident in the Board area.”
It was suggested that user views (actual and potential) are one aspect of societal views, but in fact there are 9 perspectives – the ‘9 Ps’:

**Discussion**

- **Person-centred**
  Concept subject to debate, competing priorities e.g. self management, potential tensions and unintended consequences (Nolte, BMJ 30 September 2017)
  - What does person-centred mean in public health? Public health takes population perspectives - “population-centred”

- **Healthcare Priorities and Societal Values**
  - Users (actual and potential) views one aspect of societal perspectives and values
  - Perspectives: 9 Ps – Patients (including carers and relatives), Public, Purchasers, Providers, Professionals, Policymakers, Politicians, Producers (manufacturers), PR (media)

It was noted that an organisation’s actions will express its priorities but these priorities are not always popular.

**Case study – In vitro fertilisation (IVF)**

*The seminar then heard a presentation from Dr Lorna Watson, Consultant in Public Health Medicine at NHS Fife, using IVF as a case study.*

A National Infertility Group was set up by Scottish Government in 2010 to

- bring together service representatives, key national bodies and stakeholder representatives
- to actively provide expert knowledge and advice to the development of existing and evolving Scottish Government policy on infertility
- and its implementation within NHS Boards.

At this time the provision of IVF varied by NHS Board. For example the waiting time varied between 0,1,2,3,4 years, the number of cycles offered could be either 2 or 3, and there were also variations in the criteria for treatment in relation to BMI (body mass index), whether one or both partners smoked, and the upper age limit. The aim of the Group was to reduce inequality of provision, and also reduce the waiting time for IVF to 12 months.

It was a large group (25 people) including experts, policy staff and patient group representatives. There had been lobbying on behalf of patients and each of the manifestos
of the main parties had a commitment to improve IVF services. The patient group was well organised and articulate.

The group used scenario modelling, looked at: NHS capacity; the significant level of self-funding (many clinics got 50% of their funding from self-funding patients); process and outcome information; the effect of change on the current backlog; and anticipated future demand. It was noted it was hard to quantify the ‘real costs’ of providing care and core definitions needed to be streamlined to compare like with like.

The group recommended that there was a need for additional investment, and that it was not possible to deliver a minimum service with the income provided by the NHS at the time.

Effectiveness and safety were key considerations. It was decided that most patients should be non-smoking, and whilst this could be seen as a social judgement, it was made because effectiveness was reduced if patients were smokers. It was agreed that the BMI limit should be 30 due to obstetric risk. It was recommended that IVF treatment should be available up to age of 40. It was also agreed that it was affordable to provide two cycles of treatments in order to get equity across Scotland, and review at a later date when this was changed to three.

Medical ethics vs public health ethics

Clinical practice, and research
“First do no harm”
Beneficence
Non maleficance
Autonomy
Justice (fairness, entitlement, equality)

Public Health Ethics involves systematic process to clarify, prioritise and justify possible courses of public health action based on:

- ethical principles,
- values and beliefs of stakeholders,
- and scientific and other information. 2015
There had been a Judicial Review in Glasgow which found that it was unacceptable under the Equality Act not to offer IVF to same sex couples, so the group agreed that IVF should be offered to same sex female couples and same sex male couples.

People asked if the criteria on smoking and BMI of 30 was discriminatory. It was felt to be justified because it was to do with specific risks, and also the effect on fertility. There had been a criteria that IVF wasn’t provided unless there were no children at home, but this was changed as it was seen as discriminatory against women, who were more likely to have resident children from a previous relationship.

By and large ministers accepted recommendations. £12m over 3 years was made available direct from the Scottish Government to IVF units, unusually not through the usual route of geographical NHS Boards. It turned out in some cases that clearing the waiting lists occurred quicker than anticipated as some on the waiting lists had already got pregnant or did nor require treatment for other reasons.

On one point, ministers went further than the recommendations. Ministers decided that there should be an allowance for women up to age 42 (rather than 40) if they met specific clinical criteria and had not previously undergone IVF. This was because in England NICE had allowed this.

Although there had been challenges in reaching consensus, it was felt to have been a very positive process, with clinicians and patients on board. It was interesting from the point of view of political priority as funding was identified to implement the recommended changes unlike some other areas of healthcare. There are equality issues about this, as other groups may not be able to make their case so effectively, or may recommend funding for less technological purposes which may be more difficult to quantify.

One consequence was thought to be that one of the private clinics in Edinburgh went out of business as a result of new criteria and people were better able to access IVF through the NHS. The result is that residents of Scotland have access to uniform and generous criteria compared to the rest of the UK. By contrast England has patchwork provision where commissioning groups may choose to follow NICE guidance or not.

In discussion the point of the type of patient group was raised. Should a wider citizen group have been involved? It was noted that you need to listen to voices that challenge powerful groups in society – the groups that don’t traditionally have a strong voice. The Public Sector Equality Duty18 was noted in that it is important to eliminate discrimination, advance equality of opportunity and foster good relations. However, it was also mentioned that there could be differential impacts of explicit criteria that indirectly affect certain groups, for

18 http://www.gov.scot/Topics/People/Equality/PublicEqualityDuties
example if BMI disproportionately affected deprived people so creating rules about BMI may inadvertently create inequalities.

Reference was again made to using deliberative processes to engage with wider societal values, and also a research approach called ‘Q methodology’ that will be explored at the next seminar.

It was noted that it was not uncommon with medicines for patient groups to receive funding from pharmaceutical companies, particularly for new medicines applications. For some this seemed like an ‘americanisation’ of the process. Patient groups are often funded from a mix of donations, government, trusts and sponsorship/biopharmaceuticals, as in this case.

“Our current hierarchy of evidence focuses on interventions and technology as opposed to service design process interventions that are relevant to integrated health and social care services.”

A point was made that the present guidance on service change is in need of refreshing, and does not seem designed for difficult prioritisation decisions. Its references to giving the ‘same priority’ to patients and public, as to clinical standards and financial considerations is not helpful in practice, as how do you achieve such a balance in making a decision? The public is not a ‘homogenous’ group with only one view. Is “popularity” sufficient? “Consultation” is not the same as a majority vote, but there are impacts on patients and campaign groups for choosing a different option. Service change guidance needs to be re-written from the point of view of making difficult prioritisation decisions. Can we ask patients to consider other perspectives? Can we ask policy makers what the impact has been of hearing patient perspectives?

‘Popularity’ is a debateable term when referring to public views, in terms of its relative ‘weight’ to what is seen as medical evidence. Are there better terms we could use?

Our current hierarchy of evidence focuses on interventions and technology as opposed to service design process interventions that are relevant to integrated health and social care services.

Summary of points made in discussion

- This is not just about technology or cost effectiveness, but other values e.g. social values like equity
- It is difficult to theorise a standard approach when specific details and context are important, and this in turn leads to difficulty in spreading good practice
- The involvement of patient/consumer groups is problematic if there is no ‘public’ view alongside this
- It is important to be aware of equalities when priority setting
- There is a difference in public expectations in health and social care

19 The hierarchy of evidence has been defined as “the relative weight carried by the different types of primary study when making decisions about clinical interventions” see https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2127173/
• Participatory budgeting and other deliberative mechanisms may offer a way to involve the public more meaningfully
• No one single approach will work for everything

Richard Norris
Visiting Fellow, Academy of Government, University of Edinburgh
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Richard.Norris@ed.ac.uk

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