

Health and Social Care Alliance Scotland (the ALLIANCE)

Response: General Medical Council's revised decision making and decision making guidance for Doctors

23 January 2019

The Health and Social Care Alliance Scotland (the ALLIANCE) is the national third sector intermediary for a range of health and social care organisations. The ALLIANCE has over 2,500 members including a large network of national and local third sector organisations, associates in the statutory and private sectors and individuals. Many NHS Boards, Health and Social Care Partnerships and Medical Practices are associate members.

The ALLIANCE's vision is for a Scotland where people who are disabled or living with long term conditions and unpaid carers have a strong voice and enjoy their right to live well.

Introduction

This response is informed by a roundtable meeting of ALLIANCE members and partners on 16 January 2019, held in partnership with the General Medical Council (GMC), to share views and discuss the revised guidance in detail. The response is also informed by a wealth of work undertaken by the ALLIANCE in relation to people powered health and wellbeing and a human rights based approach to the rebalancing of decision making between people who use support and services, unpaid carers and professionals who support them. It also is informed by responses from a survey conducted by ALLIANCE member organisation COPE Scotland with people who access their one to one service.

Will this guidance support patient decision making?

The emphasis on shared decision making between Doctors and people who use support and services is a welcome change of direction, however our members feel that practical, wholesale change is unlikely as a result of the introduction of new guidance alone. They have often experienced the impact of Doctors who do not “buy in” to the principles of shared decision making – and this has an impact on their level of involvement in their care and support.

Stronger language is required in some sections to ensure that the wishes and knowledge of someone's own condition must be part of the decision making process.

In paragraph 9 of Part 1, page 8, there should be a “must” in the opening line to reflect the importance of Doctors taking the person’s views and knowledge into account. Doctors must give weight to the patient’s wishes and self-knowledge rather than merely consider it important.

Doctors must ensure that the practice of shared decision making places the needs and preferences of the person using support and services at the centre of decision making in order to recognise their rights. An individual’s expertise regarding their own health and wellbeing should be given as much consideration as professional expertise or medical guidelines. Any work on shared decision making must aim to create a model of care where people using support and services are supported and empowered to make informed choices. Power must be balanced equally between people who use support and services and professionals and decisions agreed by both parties.

We believe that the guidance should be amended to include reference to examples of discussions where shared decision making is appropriate. In their publication on making shared decision making a reality, The Kings Fund¹ recognise the following examples where shared decision making should be implemented, where professionals and people using support and services are deciding whether/how to:

- Undergo a screening or diagnostic test
- Undergo a medical or surgical procedure or not
- Participate in a self-management education programme or psychological intervention
- Take medication
- Attempt a lifestyle change.

Supported decision making is a principle which is hard to measure – and often our members have experienced situations where Doctors do not understand how people who use support and services, and their unpaid carers, can help. It is unclear from the guidance how Doctors’ understanding of, and implementation of, the principles of shared decision making will be assessed.

Members did, however, believe that the production of the guidance was a step in the right direction and allowed them to express the need for Doctors to place a greater emphasis on the importance of shared decision making. This relates closely to the recommendations of the Chief Medical Officer’s Realistic Medicine publication² which notes the “imperative for a system and values change that rebalances

¹ https://www.kingsfund.org.uk/sites/default/files/Making-shared-decision-making-a-reality-paper-Angela-Coulter-Alf-Collins-July-2011_0.pdf

² <https://www2.gov.scot/resource/0049/00492520.pdf>

decision making power, where the expertise of professionals is valued equally to the expertise that people have about themselves.”

The revised guidance notes that Doctors “should involve carers, relatives and anyone else” the person using support and services wants to be involved. Specific and detailed reference should be made to the role of unpaid carers, their value as supportive decision makers and the various options (including power of attorney) that they may have chosen to take up in order to add to the decision making process. Members of the ALLIANCE who are, or who have been, unpaid carers previously have shared experiences of their views not being taken into account, even when they could have added value to the final decision made by a healthcare professional. It is important to recognise that unpaid carers have a significant level of experience that they can share and can often be the conduit for communicating or making a decision when the person who is using the support or service is unable to express their view directly to the healthcare professional.

The implementation of new guidance is critical, and we believe that people who use support and services on a regular basis should be involved in supporting the GMC’s communication about the revised guidance.

The GMC should consider the longer term benefits of ensuring a greater emphasis is placed on shared decision making during training for healthcare professionals and for junior Doctors. Our members believe that what would make the most impact is if terms like “person centredness”, #hellomynameis and “rights based approach” were given practical demonstration during training, support and revalidation. This isn’t just “about being nice” but a wholesale change in the culture and nature of a public service.

Scotland’s House of Care programme³ works to make Care and Support Planning conversations routine for people living with one or more long term condition. The St. Triduana’s Practice in Edinburgh, for example, has demonstrated the benefits of implementing care and support planning within a House of Care framework for people with long term conditions.

The practice team attended session on care & support planning (CSP) using the House of Care, supported by British Heart Foundation, Health and Social Care Alliance Scotland and Scottish Government.

The practice was keen to use CSP to deliver Realistic Medicine aspirations of more honest conversations, pragmatic approaches to medical treatments and focus on ‘more than medicine’ in partnership with the people they serve. CSP consistent with

³ <https://www.alliance-scotland.org.uk/blog/news/british-heart-foundation-launches-house-of-care-evaluation-report/>

new GMS contract and good way to deliver patient focused medical care in place of the Quality and Outcomes Framework (QoF).

Ultimately, the ALLIANCE believes that the notion of shared decision making should support the path to the progressive realisation of “supported decision making” between healthcare professionals and people using support and services. Whereas “shared decision making” implies talking through options and reaching a consensus, a truly human rights based approach to consent would place the emphasis on going through all of the options and what might happen as a result, and then the individual coming to a choice about what they want to happen.

Are the options outlined in relation to time and resource constraints helpful?

ALLIANCE members were keen to recognise that the treatment and support they got from Doctors was often of excellent quality. Despite this, structural and systemic issues, such as limited access to GPs, waiting times and focus on targets, often hindered the emphasis placed on the principles of person centredness and shared decision making.

“I have a fabulous GP who always listens and is very helpful. When I was having serious medical treatment, he explained everything without being asked to repeat things to me and my daughter if I was unable to attend any appointment. He would always speak to me over the phone or speak to my daughter. Even now he asked how I am when my daughter has an appointment. He is like the old days when a family doctor took time.”

When ALLIANCE members encountered healthcare systems that left them feeling hurried, ignored, or humiliated, the question of empowerment and decision making becomes more essential. When individuals felt respected, when they felt their questions were answered and they were listened to, we found that many individuals were comfortable with the concept of their Doctor deciding what treatment or medication would be best.

It is also important that Doctors acknowledge that things can change over time and often people will require space and time to consider their choices – informed by information from the Doctor. This should also acknowledge that people will want to discuss their options with family members and broader support networks if they wish.

Doctors holding consultations with people who use support and services must ensure that these are structured around the agenda of the person. Our members tell

us that, this alone, would require significant culture change as many Doctors do not currently operate in a facilitative or supportive manner.

“In appointments GPs are going through their tick list of things to ask meanwhile patients have come in thinking about what they want to say and are looking to interject to say what’s on their ‘shopping list’ and as a result they get confused, worked up or forget all that they wanted to share. There is a fear of being punted out the door before you’ve said what you need to say.” **ALLIANCE member**

We believe that the GMC should consider revising the draft guidance to include explicit reference to tools which could support good consultation and that facilitate shared decision making methods. Advance Statements, for example, are a powerful tool that can help people articulate their needs and wishes when subject to mental health law. Unfortunately there is a lack of awareness that such a tool exists and very few people have written an advance statement.

Is there anything else we should add in relation to maximising patients’ ability to make a decision?

Paragraph 24 in this section, on page 10, notes that “if a patient is likely to have difficulty retaining information, you should offer them a record of your discussions, detailing what decisions were made and why.” However, we are concerned that it may not always be easy to clearly distinguish between those who may or not retain the information they have been given. A record of your discussions with a Doctor should be available whether or not you are considered to have understood by the Doctor. Our members note that there is always scope for someone who is accessing support and services and doctor to think they are agreeing to or understanding the issue the same way when they may not be and that establishing trust and avoiding misunderstanding at the outset would be better achieved if everyone was able to access a record of the discussion.

The revised guidance should also reflect the following:

- That basic communication issues can create significant barriers to shared decision making.
- Hearing loss, for example, is often not treated sensitively by Doctors. It must be clear that the person understands the message they are being communicated.
- There are a range of mechanisms for establishing whether someone gives their consent – many of which are not conventional e.g. the use of dry boards and what matters to me boards.

- Some people may not be prepared for collaborative conversations, and so Doctors need to be prepared to explain that people have a choice over treatment – otherwise it may be assumed that “Doctor knows best”.
- Avoid “tick box” lists or options for people. That might appear to be “support” but it can dehumanise what can be a deeply emotional experience. Options should be discussed in detail and with compassion.
- Information should be made available to people about their choices, at the right time and in a variety of formats.
- Training is available in working with people and customer service skills.

Will this guidance help patients understand benefits and harms?

The recommendations for Doctors around helping people who use support and services to understand benefits and harm are helpful. In addition to the use of pictures and infographics, which are also promoted in the Scottish Government’s Health Literacy Action Plan⁴, we would suggest considering:

- The promotion of a range of existing measures that relate to good communication including the ‘Teach Back’ technique⁵ which goes beyond saying “do you understand?” and checks how things have been explained and whether it the discussion has been effective or not.
- Accessible information and guidance on a variety of long term conditions and/or treatment methods in a range of formats including easy read, BSL, braille, Makaton, large print.
- Working with local support agencies and third sector organisations (which can be accessed through ALISS⁶) to access information about local support and guidance for people living with particular conditions who may have received a range of related treatments.

Will this guidance support patients who don’t want to be involved?

Where a patient is able to make the decision and give consent

There will be circumstances where someone chooses not to make decisions themselves and would prefer that the Doctor made a decision or that this was deferred to their unpaid carer or another person from their social circle. People can actively make this decision, but it needs to be clear that they have done this. A Doctor should not make this decision on someone’s behalf, and we support the proposal that the person’s decision must be recorded by the Doctor.

⁴ <https://www2.gov.scot/Resource/0052/00528139.pdf>

⁵ <http://www.healthliteracyplace.org.uk/media/1295/teach-back-postcard.pdf>

⁶ <https://www.aliss.org/>

We also welcome the suggestion in the revised guidance that people are welcome to change their mind about not wanting to be involved. There will be circumstances where over time someone wants to add their view, having been given time to consider the facts and consequences of any treatment.

The revised guidance should be amended to note the legal rights that other people have to speak on behalf of people who use support and services, for example, independent advocates and people who have been granted power of attorney. These roles not only carry legal powers in Scotland (independent advocates through the Mental Health (Scotland) Act 2015 and power of attorney through the Adults With Incapacity Act 2000) the people performing these roles can substantially inform the process of making an appropriate shared decision and must not be underplayed in the final guidance note.

The guidance outlines that if a doctor is concerned that a patient is making a decision that is unwise for them, the doctor should explain their concerns clearly and explain what might happen as a result of the decision. Doctors are of course expected to offer their clinical judgement but should be aware of how their own wishes and preferences might influence the advice they give and must not put pressure on a patient to accept that advice. Do you agree with this guidance?

Clearly explaining the consequences of a decision which the Doctor may consider unwise is a critical part of the supported decision making process. Each discussion about risk should cover the risks and the probability of them occurring. These discussions should be properly recorded and pressure should never be put on any individual to make a particular choice, or that they must accept the advice they are given.

Is there anything else we could do in relation to where a patient may lack the capacity to make the decision?

We believe that amendments could be made to the guidance to highlight:

- The various elements of mental health law which apply in different parts of the UK and will dictate how Doctors work with people who are subject to them.
- Highlighting good practice examples, such as advance statements which can help people articulate their needs and wishes before they reach a crisis point.
- A range of accessible information on consent and decision making related to incapacity should be made available.

Are these the right principles?

Generally these principles reflect the requirements of the approach promoted within the revised guidance. We would, however, suggest that the GMC considers including reference to adopting an open minded approach, that the principles of person-centredness should be included and that continuous improvement and learning from complaints are a key part of ensuring a human rights based system which values the views of people who use support and services.

The paragraph explaining the principle to **recognise the importance of the decision-making process**, would be plainer if it began with “The way in which the patient gives consent is less important...” and concludes by noting the requirement to accurately record the discussion and decision. This is imperative, rather than noting that “although it is important” which could be perceived to weaken its importance when expressed that way.

There is some ambiguity in the final two principles. The last principle identifies people who may lack capacity, as the term “overall benefit” is used and it has already been defined on page 4. However, the penultimate paragraph on page 5 uses the term “where they cannot make a decision”. We are not clear if that is a reference to someone who lacks capacity – if so there should be consistency in the use of the word “overall benefit” – or if it means, for example, someone who doesn’t want to make a decision but has full capacity.

General comments

ALLIANCE members commented that the words “must” and “should” are too closely associated as interchangeable throughout the document. It was suggested that the definition of these terms (outlined on page 2) should be amended to ensure that “should” is based on an objective test where the doctor should act in a particular way where possible, from the stand point of an impartial informed observer.

ALLIANCE members also commented that the “Relationship between this guidance and action against a doctor’s registration” section on Page 3 would benefit from some re-ordering and deletion. This should set up the point made in the current paragraph 3 that failure to follow the guidance per se does not mean a doctor is negligent. However, the wording “This is because the guidance sets out the principles of good practice, not thresholds for taking action to protect the public” could be better worded to explain that whilst the guidelines are just that – guidelines on good practice – they should not be seen as the ceiling of the action expected to be taken to meet professional standards. The term “thresholds” is too ambiguous – is it the lowest threshold, or the highest threshold?

Members believe that the legal annex, which it is noted in footnote 7 of page 15, should be made available for consultation before it is adopted.

Comments on resources

All resources must be produced in a variety of accessible formats, available online and through third sector organisations, providers of health and social care services, local authorities, the Scottish Government and other bodies with connections to disabled people, people with long term conditions and unpaid carers.

Equality & Diversity Comments

The GMC should consider the role that seldom heard groups (starting with those who are described under the protected characteristics of the Equality Act 2010) can be consulted directly on their experiences with Doctors and the type of advice and support around shared decision making they require. Recent participatory action research highlighted the different experiences of the healthcare system experienced by asylum seeking women and homeless people in Scotland⁷, for example. Agencies need to hear directly from people who have a range of protected characteristics in order to address the issues raised.

For more information

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⁷ <https://strathprints.strath.ac.uk/58209/>