Response ID ANON-8U9V-Z3H9-A

Submitted to Consultation on a Patient Safety Commissioner Role for Scotland Submitted on 2021-05-28 17:11:09

Questions

1 Do you agree that the Patient Safety Commissioner role should first focus on medicines and medical devices, as set out in the Cumberlege Review?

Nο

Please give reasons for your response in the box below. Please be as specific as you can, and include any resources or references to evidence on this topic that we should consider.:

Inclusion of medicines and medical devices within the patient Safety Commissioner's remit is very important, of course. However it is equally important that the remit does not end there. Psychosocial and behavioural interventions are widely recommended within the NHS for the ever-expanding range of patients. There is currently no UK mechanism for recording or monitoring harms from these types of interventions. Change in this regard is long overdue. In the interest of patient safety it is vital that the impact on patients of following advice on activity, including exercise, falls within the ambit of the Patient Safety Commissioner from the outset.

Health professionals require to prescribe behavioural interventions involving activity modification with as much care as medicines. The wrong advice can and does lead to harm. No structures exist in Scotland which address this, not even an equivalent to the 'Yellow Card' reporting of adverse response to medicines. It would appear that the NHS in Scotland operates with an expectation that any harm will be notified via a complaint, ergo in the absence of complaints all is well. This was certainly the view purveyed when I met, as one of the patient group 'Taking ME Forward' [TMEF], with a group of high level nursing and allied health professionals in July 2015. The purpose of the meeting was to highlight adverse outcomes experienced by people with ME following advice to exercise and the lack of a framework to address this. The meeting was the outcome of written communication initiated by TMEF, commencing with a letter to then CMO Harry Burns in February 2014. We were given time to make the case and a courteous hearing. However the meeting was not minuted and, as far as I'm aware, noting has changed.

2 If the role were to expand in the future, which specific aspects of patient safety do you feel the Patient Safety Commissioner should focus on?

Please give reasons for your response in the box below. Please be as specific as you can, and include any resources or references to evidence on this topic that we should consider.:

For the reasons given at Q1, the impact on patients of following psychosocial / behavioural / activity advice should fall under the ambit of the Safety Commissioner from the start. Attention to addressing these aspects of patient safety is urgent and overdue, and must be addressed as soon as possible.

3 Do you believe that the Patient Safety Commissioner should be independent of the Scottish Government?

Yes

Please give reasons for your response in the box below. Please be as specific as you can, and include any resources or references to evidence on this topic that we should consider.:

4 Do you believe that the Patient Safety Commissioner should be independent of the NHS?

Yes

Please give reasons for your response in the box below. Please be as specific as you can, and include any resources or references to evidence on this topic that we should consider.:

5 Who should the Patient Safety Commissioner be accountable to?

Please give your answer, and reasons for your response, in the box below. Please be as specific as you can, and include any resources or references to evidence on this topic that we should consider.:

I note with interest that two possible models in respect of the appointment and accountability of an independent commissioner are set out in the consultation paper. Each model may have pros and cons. I'm not in a position to judge which of the two would be best.

6 How much do you know about existing policies and organisations already in place (listed in table 1 on page 11 of the consultation document) to support patients' voices to be heard within the healthcare system?

Please select the answer which best describes your level of awareness:

Very aware (I have heard of all of them)

Please give reasons for your response in the box below. Please be as specific as you can, and include any resources or references to evidence on this topic that we should consider.:

Please see comments regarding each of the respective policies and organisations at Q7. (I am unclear at which question feedback on these is being sought. The present question appears to relate to how I come to know about them.)

7 In your view, despite the existing ways patients can make their voices heard (listed in table 1 on page 11 of the consultation document), why do you think people still feel that this is not happening?

Please give your response in the box below. Please be as specific as you can, and include any resources or references to evidence on this topic that we should consider.:

PATIENT RIGHTS (SCOTLAND) ACT 2011 - Does not cover safety. Despite 'safety' having been one of the 8 areas included in consultation proposals. The only occurrence of 'safe', safety' or 'safety' is in connection with the environment in which care is delivered: i.e. "Patients are cared for in an appropriate environment which is as clean and safe as is reasonably possible." As articulated in the latest version of the Learning from adverse events through reporting and review framework:

http://www.healthcareimprovementscotland.org/our_work/governance_and_assurance/learning_from_adverse_events/national_framework.aspx patients' rights are confined to giving feedback, making comments, raising concerns and making complaints.

CHARTER OF PATIENT RIGHTS AND RESPONSIBILITIES - The right to safe and effective care is stated in the Charter however this does not reflect any provision in the Patients Rights Bill. In this and other respects the Charter lacks teeth.

NHS COMPLAINTS PROCESS; SCOTTISH PUBLIC SERVICES OMBUDSMAN; PATIENT ADVICE AND SUPPORT SERVICE - Important though it is that robust complaints processes exist, with an Ombudsman representing the final stage in this process, and that patients have access to support to make complaints, these systems and structures do not in themselves ensure safe care. Nor should the existence of a complaints process be viewed as somehow equivalent to or substituting for a reporting procedure for adverse reactions and harms.

CARE OPINION - A valuable means of providing feedback, but no guarantee of patient safety.

REGULATORY BODIES - While it is important that fitness to practise concerns can be raised through professional regulatory bodies, this is of limited value in terms of an overarching goal of ensuring patient safety. Reasons: (i) only serious concerns can be addressed; (ii) not all patients / patient representatives will be minded and able to do this; (iii) even if inclined and able they are likely to be dealing with a demanding and difficult situation in terms of their / their relative's healthcare and may not have the scope to make a report; (iv) it is quite possible that the default position of the professional body is fend off concerns raised and defend the professional involved if at all possible.

ORGANISATIONAL DUTY OF CANDOUR PROCEDURE - This, uniquely among the items listed, has legal force. Extending the force of law to other areas is required in order to ensure more robust patient safeguards.

MEDICINES AND HEALTHCARE PRODUCTS REGULTORY AGENCY YELLOW CARD SCHEME - Widely recognised as under utilised; applies only to medicines and healthcare products - does not apply to behavioural interventions such as 'active rehabilitation'.

8 In your view, what should the main functions of the Patient Safety Commissioner be?

Please give your response in the box below. Please be as specific as you can, and include any resources or references to evidence on this topic that we should consider.:

To help ensure that safe advice is given in the first place. To help ensure that accountability and learning follow adverse experiences. At the same time helping ensure a culture of openness and learning in the NHS, so that staff are not afraid to admit faults or mistakes, nor to acknowledge that their patient has deteriorated.

9 What skills and expertise do you think the Patient Safety Commissioner needs to carry out their role?

Please give your response in the box below. Please be as specific as you can, and include any resources or references to evidence on this topic that we should consider.:

10 What support do you think the Patient Safety Commissioner would need?

Please give your response in the box below. Please be as specific as you can, and include any resources or references to evidence on this topic that we should consider.:

11 Do you think that the Patient Safety Commissioner role should be established in law?

Yes

Please give reasons for your response in the box below. Please be as specific as you can, and include any resources or references to evidence on this topic that we should consider.:

Good intentions and warm words abound - and have done for some time. Statutory powers are essential if progress is to be made. While this may mean that the new Commissioner takes longer to be up and running, there is little point in doing something quickly if it doesn't secure change. As the Ministerial Foreword advises: "there is still much work to be done to make sure that patients' voices are not only heard, but are listened to and acted on, and that patients and members of the public feel that they can play a part in changing the service."

12 What are your views on how creating a Patient Safety Commissioner might affect the protected characteristics of age, disability, sexual orientation, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion or belief, and sex?

Please give your response in the box below. Please be as specific as you can, and include any resources or references to evidence on this topic that we should consider.:

13 The Fairer Scotland Duty places a legal responsibility on certain public bodies in Scotland to actively consider how they can reduce inequalities caused mainly by people's financial situation. What are your views on how having a Patient Safety Commissioner might affect this inequality?

Please give your response in the box below. Please be as specific as you can, and include any resources or references to evidence on this topic that we should consider.:

14 If you live in an island community, what are your views on how having a Patient Safety Commissioner might affect access to safe, high quality public services where you live?

Please give your response in the box below. Please be as specific as you can, and include any resources or references to evidence on this topic that we should consider.:

15 What are your views on how having a Patient Safety Commissioner might affect respecting, protecting and fulfilling the rights of children and young people as set out in the UN Convention on the Rights of the Child?

Please give your response in the box below. Please be as specific as you can, and include any resources or references to evidence on this topic that we should consider.:

16 Do you have any further comments on the Patient Safety Commissioner role that you haven't covered in your responses to the previous questions?

Please give your response in the box below. Please be as specific as you can, and include any resources or references to evidence on this topic that we should consider.:

About you

17 What is your name?

Name:

Helen Brownlie

18 What is your email address?

Email:

hm.brownlie@virginmedia.com

19 Are you responding as an individual or an organisation?

Organisation

20 What is your organisation?

Organisation:

The 25% ME Group

21 The Scottish Government would like your permission to publish your consultation response. Please indicate your publishing preference:

Publish response with name

22 We will share your response internally with other Scottish Government policy teams who may be addressing the issues you discuss. They may wish to contact you again in the future, but we require your permission to do so. Are you content for Scottish Government to contact you again in relation to this consultation exercise?

Yes

23 I confirm that I have read the privacy policy and consent to the data I provide being used as set out in the policy.

I consent

Evaluation

24 Please help us improve our consultations by answering the questions below. (Responses to the evaluation will not be published.)

Matrix 1 - How satisfied were you with this consultation?:

Very satisfied

Please enter comments here .:

Matrix 1 - How would you rate your satisfaction with using this platform (Citizen Space) to respond to this co Very satisfied	nsultation?:
Please enter comments here.:	