Mental Health and Wellbeing Strategy Consultation

Scottish Government
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RESPONDENT INFORMATION FORM

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Are you responding as an individual or an organisation?

☐ Individual

X☐ Organisation

Full name or organisation's name

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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

☐ No

QUESTIONS - PART 2

MENTAL HEALTH AND WELLBEING STRATEGY – OUR DRAFT VISION AND OUTCOMES

2. Our Overall Vision

- **2.1** On page 5 we have identified a draft vision for the Mental Health and Wellbeing Strategy: 'Better mental health and wellbeing for all". Do you agree with the proposed vision? **[Y/N]**

- **2.2** If not, what do you think the vision should be?

YES

- **2.3** If we achieve our vision, what do you think success would look like?

We believe that to be wholly successful the vision needs to acknowledge the link between chronic conditions, such as Inflammatory Bowel Disease (IBD), and the significant impact that living with a physical health condition has on mental health and wellbeing.

3. Our Key Areas of Focus

- **3.1** On page 5, we have identified four key areas that we think we need to focus on. Do you agree with these four areas? **[Y/N]**
- **NO**
- **3.2** If not, what else do you think we should concentrate on as a key area of focus?

While we support the four key areas of focus within the strategy, we would suggest that they are expanded to specifically acknowledge the impact on mental health and psychological wellbeing that a diagnosis of a chronic, incurable and fluctuating condition, such as Inflammatory Bowel Disease (IBD) has.

4. Outcomes

- **4.1** Below are the outcomes that people have said they would like this refreshed mental health and wellbeing strategy to achieve. Some of these describe how things might be better for individuals, some for communities, and some for the whole population of Scotland. Do you agree that the Mental Health and Wellbeing strategy should aim to achieve the following outcomes for people and communities?

1. Strongly agree	2. Agree	3. Neutral	4. Disagree	5. Strongly disagree

This will help us to understand what is most important to people and think about what our priorities should be. **Please indicate your selection with a tick under the corresponding number:**

Individuals	**1**	**2**	**3**	**4**	**5**
People have a shared language and understanding of mental health and wellbeing and mental health conditions	√				
People understand the things that can affect their own and other's mental health and wellbeing, including the importance of tolerance and compassion	√				
People recognise that it is natural for everyday setbacks and challenging life events to affect how they feel	√				
People know what they can do to look after their own and other's mental health and wellbeing, how to access help and what to expect	√				
People have the material, social and emotional resources to enable them to cope during times of stress, or challenging life circumstances	√				
People feel safe, secure, settled and supported	√				
People feel a sense of hope, purpose and meaning	√				
People feel valued, respected, included and accepted	√				
People feel a sense of belonging and connectedness with their communities and recognise them as a source of support	√				
People know that it is okay to ask for help and that they have someone to talk to and listen to them	√				
People have the foundations that enable them to develop and maintain healthy, nurturing, supportive relationships throughout their lives	√				
People are supported and feel able to engage with and participate in their communities	√				
People with mental health conditions are supported and able to achieve what they want to achieve in their daily lives	√				
People with mental health conditions, including those with other health conditions or harmful drug and alcohol use, are supported to have as good physical health as possible	√				
People living with physical health conditions have as good mental health and wellbeing as possible	√				
People experiencing long term mental health conditions are supported to self-manage their care (where appropriate and helpful) to help them maintain their recovery and prevent relapse	√				
People feel and are empowered to be involved as much as is possible in the decisions that affect their health, treatment and lives. Even where there may be limits on the decisions they can make (due to the setting, incapacity or illness), people feel that they are supported to make choices, and their views and rights will be respected	√				

Services and Support	**1**	**2**	**3**	**4**	**5**
A strengthened community-focussed approach, which includes the third sector and community-based services and support for mental health and wellbeing, is supported by commissioning processes and adequate, sustainable funding	x				
Lived experience is genuinely valued and integrated in all parts of our mental health care, treatment and support services, and co-production is the way of working from service design through to delivery	x				
When people seek help for their mental health and wellbeing they experience a response that is person-centred and flexible, supporting them to achieve their personal outcomes and recovery goals	x				
We have a service and support system that ensures there is no wrong door, with points of access and clear referral pathways that people and the workforce understand and can use	x				
Everyone has equitable access to support and services in the right place, at the right time wherever they are in Scotland, delivered in a way that best suits the person and their needs	x				
People are able to easily access and move between appropriate, effective, compassionate, high quality services and support (clinical and non-clinical)	x				
Services and support focus on early intervention and prevention, as well as treatment, to avoid worsening of individual's mental health and wellbeing	x				

Do you have any comments you would like to add on the above outcomes?

It is estimated that around 2 million people in Scotland have at least one long-term condition that brings with it significant human, social and economic costs.[1] The link between long-term conditions and mental health is well-established and consistently demonstrates that people with long-term conditions are two to three times more likely to experience mental health problems than the general population.[2]

Therefore, whilst we welcome many of the outcomes listed above, we believe that improvements to service provision and access to psychological support must recognise and include people living with long term conditions, such as Inflammatory Bowel Disease (IBD).

People living with Crohn`s Disease and Ulcerative Colitis, the two main forms of IBD, live with complex disease, intestinal failure and issues related to pain, previous surgery, and the challenges their disease presents to them on a day to day basis. The impact of the condition can be profound, leading to time off school and work, withdrawal from social relationships and an inability to carry out everyday activities such as shopping and exercise. Almost half (45%) of respondents who took part in a Crohn's & Colitis UK Quality of Life survey reported that IBD had stopped them reaching their full potential in life in general.[3]

A 2016 systematic review by Neuendorf *et al* (2016) found that 21% of people with Crohn's or Colitis in their study experienced clinical anxiety disorders, whilst 35% experienced symptoms of anxiety.[4] The research also found that 15% of people with Crohn's or Colitis had a depressive disorder, whilst 22% reported depressive symptoms.[4] A study by Hoogkamer *et a*l (2021) also found high levels of psychiatric morbidity in people living with Crohn's or Colitis with 67.9% of participants experiencing anxiety, 33.6% experiencing depression, 18.3% reporting suicidal ideation and 22.7% admitting to self-harm [5.]

Emerging evidence is showing that not only do these psychiatric comorbidities affect an individual patient's quality of life these disorders are also associated with a more severe disease course and increased healthcare resource utilisation.

A recent study by Hill *et al*., (2022) found that patients with Crohn's and Colitis who also experienced psychiatric disorders spent more days in in the hospital (median, 7 days vs. 5 days, $p < 0.01$), experienced higher 30-day (31.3 vs. 25.4%; $p < 0.01$) and 90-day (42.6 vs. 35.3%, $p < 0.01$) readmission rates, and had higher hospitalisation-related costs (median, $41,418 vs. $39,242, $p < 0.01$).[6]

For people living with Crohn's and Colitis, psychological support is essential and is required from diagnosis, throughout ongoing care and during both medical and surgical treatments. The following nationally recognised guidelines and Standards highlight this necessity:

British Society of Gastroenterology (BSG) IBD Guidelines[7]:

- Statement 118 – We suggest that in patients with IBD, Psychological therapies including CBT, hypnotherapy and mindfulness meditation be offered to interested patients, particularly those with psychological symptoms as adjunctive therapy to improve symptom control and Quality Of Life.

- Good practice recommendation 25 – IBD patients experiencing fatigue should be investigated for psychological symptoms.

- Statement 119 – We suggest that psychological interventions may be useful for IBD patients with pain where no physical cause can be found, and may be offered as adjunctive therapy.

- Statement 120 – We suggest that patients with disabling fatigue in whom no correctable metabolic deficiency is found may be directed to supportive psychotherapy, stress management or graded exercise.

IBD UK Standards 2019[8]:

- Statement 3.1 - All newly diagnosed IBD patients should be seen by an IBD specialist and enabled to see an adult or paediatric gastroenterologist, IBD nurse specialist, specialist gastroenterology dietitian, surgeon, psychologist and expert pharmacist in IBD as necessary.

- Statement 3.2 **-** After diagnosis, all patients should have full assessment of their disease, nutritional status, bone health and mental health, with baseline infection screen, in order to develop a personalized care plan.

- Statement 5.4 **-** Patients with IBD being considered for surgery should be provided with information in a format and language they can easily understand to support shared decision making and informed consent and offered psychological support.

- Statement 6.8 **-** On admission, patients with IBD should have an assessment of nutritional status, mental health and pain management using validated tools and be referred to services and support as appropriate.

- Statement 7.4 - Pain and fatigue are common symptoms for IBD patients and should be investigated and managed using a multidisciplinary approach including pharmacological, non-pharmacological and psychological interventions where appropriate.

Despite research findings, national clinical guidance and the IBD Standards, psychiatric complaints in IBD patients are undertreated. Six in 10 (60%) of patients responding to The IBD UK Patient Survey 2019[9] reported that they were not asked about their mental health during medical appointments. Of those recently diagnosed only 10% of respondents reported that how well they were coping emotionally had been assessed.

"[My] *Mental health has massively affected me since diagnosis and I am still struggling. This has never been discussed in all the appointments and admissions I've had, and it needs to improve or young people with the disease are just going to struggle even more"*
Patient Quote

"I have suffered with anxiety for most of my adult life. However after my diagnosis I quickly suffered a mental breakdown. I feel more immediate aftercare would of helped me. Someone to talk to about Crohn's & to help process a diagnosis of a life long condition. I was sign posted to the Crohns- Colitis website however at a time of crisis looking at a website for information is very overwhelming & impersonal"
Patient Quote

A recent pan Scotland IBD service mapping exercise carried out by the National IBD Steering Group of the Modernising Patient Pathways Programme (MPPP) highlights that there is currently only one IBD Service in Scotland that meets the above standards regarding access to psychological support.

Intervention has been shown to work. An evaluation of integrated psychological support for patients with IBD found that the most common reason for referral into the service was for support adjusting to IBD and its symptoms. The study concluded that for every £1 spent on the pilot project[10]:

- The number of bed days reduced by more than 60%
- Inpatient admissions reduced by over 70%
- IBD follow up appointments reduced by 60%
- Number of scans reduced by 75%.

In order to achieve the laudable ambition of "Better mental health and wellbeing for all" equitable access to high quality service provision must be commissioned to include those people for whom their physical condition has a direct impact on their mental health and wellbeing.

References:

[1] Healthcare Improvement Scotland (2022). *Long-term conditions*. https://www.healthcareimprovementscotland.org/our_work/long_term_conditions.aspx

[2] Naylor, C., Parsonage, M., McDaid et al., (2012). *Long-term conditions and mental health: The cost of co-morbidities*. Long-term condition and mental health Chris Naylor February 2012 (kingsfund.org.uk)

[3] Crohn's & Colitis UK (2018) *Quality of Life Membership Survey*.

[4] Neuendorf R, J. *et al.*, (2016). Depression and anxiety in patients with Inflammatory Bowel Disease: A systematic review. *Psychosom Res*, 87, p.70-80.

[5] Lamb, C. A. *et al.*, (2019). British Society of Gastroenterology consensus guidelines on the management of inflammatory bowel disease in adults. *Gut*, 68 (Suppl 3):s1-s106.

[6] Hill, E., Nguyen, N.H., Qian, A.S. *et al.* (2022). Impact of Comorbid Psychiatric Disorders on Healthcare Utilization in Patients with Inflammatory Bowel Disease: A Nationally Representative Cohort Study. *Dig Dis Sci*, 67, 4373–4381.

[7] IBD UK (2019) *IBD Standards 2019*. Homepage | IBD UK

[8] IBD UK (2021). *Crohn's and Colitis Care in the IK: The Hidden Cost and a Vision for Change*. Crohn's and Colitis Care in the UK: The Hidden Cost and a… | IBD UK

[9] Hoogkamer, A. B., Brooks, A. J., Rowse, G. *et al.*, (2021). Predicting the development of psychological morbidity in inflammatory bowel disease: a systematic review. *Frontline Gastroenterology*, 12, p.137-144.

[10] Eccles, J. A., Ascott, A., McGeer, R., *et al* (2021). Inflammatory bowel disease psychological support pilot reduces inflammatory bowel disease symptoms and improves psychological wellbeing. *Frontline Gastroenterology*, 12, p. 154-157.

Information, data and evidence	1	2	3	4	5
People who make decisions about support, services and funding use high quality evidence, research and data to improve mental health and wellbeing and to reduce inequalities. They have access to infrastructure and analysis that support this					

Do you have any comments you would like to add on the above outcome?

We support the outcome above but would welcome additional information describing how transparency in the research, evidence and data sources used will be ensured. We'd also like more information on how Third Sector organisations, particularly medical research charities, will be involved in providing this research and evidence.

Medical research charities such as Crohn's & Colitis UK are an integral part of the UK's health research system. We respond to the priorities of people living in the UK and ensure that research into these diseases is relevant, necessary and impactful. In their 2021 impact report, the Association for Medical Research Charities estimated that in the past two decades over 10,000 grants from 49 charities have led to over 73,000 publications that have helped shape medical knowledge and over 4,000 influences on policy and practice that help advance healthcare.

Crohn's & Colitis UK has been driving world class research since 1979, awarding over £11.5 million in grants to date. The researchers we fund are well respected in their field and many have gone on to publish papers, receive further funding, and inform improvements in health care for people with Crohn's and Colitis thanks to their findings.

For example, our most recent research into the prevalence and incidence of Crohn's and Colitis was carried out by scientists at the University of Nottingham and is the largest of its kind worldwide. The study involved researchers analysing the health care records of 38.3 million people registered with GPs to identify the number of people living with Crohn's or Colitis across the UK.

Furthermore, information that we provide to our community has been awarded the Patient Information Forum's PIF TICK accreditation, which requires following a rigorous process to ensure our patient information is evidence based and easy to understand.

12. Funding

- **12.1** Do you think funding for mental health and wellbeing supports and services could be better used in your area? **[Y/N]:**

- **12.2** Please explain the reason for your response above.

As previous described, currently only one IBD service in Scotland is adequately resourced to ensure that people with Crohn's and Colitis have access the psychological support they require to manage their condition. NHS Boards should therefore ensure that IBD services receive adequate funding and staff resources to meet the BSG and IBD standards regarding psychological care.