PEOPLE WITH INTELLECTUAL DISABILITY AND MENTAL HEALTH/BEHAVIOURAL PROBLEMS: GUIDANCE ON COVID-19 FOR INPATIENT SETTINGS
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INTRODUCTION

1.1 There are approximately 1.2 million people with an intellectual disability (ID) in the UK. They have comorbid mental health problems at a rate of about 40%, which is substantially higher than the general population. About 21% of them are in contact with specialist health services and about 0.16% (1955) are in in-patient psychiatric settings.

1.2 These in-patient psychiatric settings include six categories- category 1: secure services, category 2- acute admission units in specialized ID units (also known as assessment and treatment units) category 3- acute admission units in mainstream mental health, category 4- forensic rehabilitation units, category 5- rehabilitation and continuing care units, category 6- other beds (specialist units for neuropsychiatric conditions, etc)

1.3 People in in-patient psychiatric settings are quite vulnerable as they have co-morbid mental and physical health conditions at a rate of a 40-84%. These include major mental illnesses, other developmental disorders, substance misuse, personality disorders and physical health conditions.

1.4 This vulnerability becomes more pronounced in the wake of the COVID-19 pandemic. The risk to this group can be conceptualized as

   a. Physical health: Increased risk of mortality and morbidity due to COVID-19
   b. Mental health: Increased risk of worsening mental health symptoms and behavior that challenges or increased risk of mental illness relapses and behavior that challenges. Some of this behavior may lead to diagnostic overshadowing- i.e., it may mask serious underlying physical conditions.

(Both of the above categories can be seen as vulnerable groups and is in line with the classification proposed by NHS England in their March 2020 document Responding to COVID-19: Mental Health, Learning Disabilities and Autism. Their proposal was to have 3 provisional vulnerable groups- (i) People whose vulnerability stems from a susceptibility to the virus, perhaps because of age or a chronic respiratory condition, (ii) People whose vulnerability stems from their mental health, such as people with an eating disorder, people with underlying conditions and frail older people, or people with a learning disability, autism or both who are dependent on carers and (iii) People whose vulnerability stems from both of the above).
1.5 This guidance provides some pointers for practicing clinicians on addressing these risks and vulnerabilities. It draws on published guidance from a range of national bodies including Public Health England, NHS England, Royal College of Psychiatrists, Royal College of Psychiatrists – ID faculty, MENCAP, RADIANT, National Autistic Society, Autistica, Challenging Behaviour Foundation, Books beyond Words, etc.

1.6 The guidance from Public Health England is being updated on a regular basis and the reader is advised to refer to the most updated version in conjunction with this guidance.

**RISK TO PHYSICAL HEALTH**

1.7 People with an intellectual disability have premature mortality in comparison to the general population and in 2018/19, 41% of those who died, died due to a respiratory cause. CIPOLD (Confidential Inquiry into Premature Deaths of People with Learning Disabilities) found that for every one person in the general population who dies from an avoidable cause, 3 people with intellectual disability die from a condition amenable to good quality care. It is a startling statistic that shows the price of diagnostic overshadowing. An updated review of other physical health vulnerabilities of people with an intellectual disability is available here.

**Assessing and categorizing**

- Public Health England has identified two groups that are at risk-
- (i) a group **at risk of severe illness** from COVID-19 who need particularly stringent social distancing measures (Box 1)
- (ii) an extremely vulnerable group who are **at very high risk of severe illness** from COVID-19 who need shielding measures (Box 2)

- Clinicians working in in-patient psychiatric settings for people with intellectual disability can use both the checklists (Boxes 1 and 2) to identify whether their patients have any of the conditions named.
- As is clear from Box 1, everyone with a learning (intellectual) disability will be identified as being in the group at ‘risk of severe illness from COVID-19’.
• In an in-patient psychiatric setting for people with an intellectual disability, the treating team has an overview of both physical and mental health care. Hence if you are using a RAG rating to quantify the patient’s risk, it would be logical to place all in-patients within the Red category. The presence of other conditions in Boxes 1 and 2 will help to further quantify and describe the risk factors.

Proactive interventions

a. Prepare a hospital passport (pay particular attention to the presence of physical problems including dysphagia, sensory deficits, etc.).

b. Prepare a COVID care plan (see Box 3) which will clearly set out the physical health risk factors for the person, the person’s functional level, etc.

Box 1: Group at risk of severe illness from COVID-19 who need particularly stringent social distancing measures

• aged 70 or older (regardless of medical conditions)
• under 70 with an underlying health condition listed below (i.e. anyone instructed to get a flu jab as an adult each year on medical grounds):
• chronic (long-term) respiratory diseases, such as asthma, chronic obstructive pulmonary disease (COPD), emphysema or bronchitis
• chronic heart disease, such as heart failure
• chronic kidney disease
• chronic liver disease, such as hepatitis
• chronic neurological conditions, such as Parkinson’s disease, motor neurone disease, multiple sclerosis (MS), a learning disability or cerebral palsy
• diabetes
• problems with your spleen – for example, sickle cell disease or if you have had your spleen removed
• a weakened immune system as the result of conditions such as HIV and AIDS, or medicines such as steroid tablets or chemotherapy
• being seriously overweight (a body mass index (BMI) of 40 or above)
• those who are pregnant

Please note that the guidance is intended for use in situations where people are living in their own homes and hence the stringent social distancing measures mentioned need to be adapted for in-patient psychiatry settings.
Box 2: Extremely Vulnerable group at very high risk of severe illness from COVID-19 who need shielding measures

People falling into this extremely vulnerable group include:

1. Solid organ transplant recipients.
2. People with specific cancers:
   - people with cancer who are undergoing active chemotherapy or radical radiotherapy for lung cancer
   - people with cancers of the blood or bone marrow such as leukaemia, lymphoma or myeloma who are at any stage of treatment
   - people having immunotherapy or other continuing antibody treatments for cancer
   - people having other targeted cancer treatments which can affect the immune system, such as protein kinase inhibitors or PARP inhibitors
   - people who have had bone marrow or stem cell transplants in the last 6 months, or who are still taking immunosuppression drugs
3. People with severe respiratory conditions including all cystic fibrosis, severe asthma and severe COPD.
4. People with rare diseases and inborn errors of metabolism that significantly increase the risk of infections (such as SCID, homozygous sickle cell).
5. People on immunosuppression therapies sufficient to significantly increase risk of infection.
6. Women who are pregnant with significant heart disease, congenital or acquired.

Please note that the guidance is intended for use in situations where people are living in their own homes and hence the stringent social distancing measures
BOX 3: COVID CARE PLAN: EXAMPLE

Patient name, Gender, Date of Birth: AB, male, 01/01/1965

1. Mr AB is a 55-year-old Caucasian male who is an in-patient in a psychiatric unit for people with intellectual disability.
2. Diagnosis (mental health): Mild Intellectual Disability, Autistic Spectrum Disorder, Paranoid Schizophrenia
3. Diagnosis (physical health): Bronchial Asthma and early COPD, no hospitalizations for that, not on regular inhalers. He is an ex-smoker who is off cigarettes for over 5 years. He has obesity with a BMI of 31 (He is not morbidly obese).
4. His current medication is Depot Olanzapine xxxxxxx and Tab Procyclidine xxxxxx. He is on PRN salbutamol inhalers that he usually does not like taking.
5. Prior to this admission, he was living in the community in supported accommodation and was healthy. At present, though not keen on exercise he has no active physical health symptoms. He carries out his daily activities with little help from others. (Can mention HONOS LD or equivalent scores, if appropriate)

Actions

1. To rate risk/vulnerability level (Action: Doctor and MDT):
   Done. Mr AB is rated as a **high risk/vulnerable patient** (RAG rating: Red). This is firstly because he has a mild learning disability, bronchial asthma and early COPD, all conditions that comes within the category of the group at risk of severe illness from COVID-19. Secondly, he is also considered to be vulnerable to having mental health distress and relapse of his mental illness.
2. To give advice on social distancing and other COVID related precautions within the unit (Action: Nursing team).
   Done and is compliant
3. To offer a structured timetable of activities on the ward (Action: Nursing & Day Services).
   Done and attends about 60% of the time
   Done and on current evidence, does have the capacity to consent
5. To give advice on procedures for isolation should that be needed (Action: Nursing team).
   Done and appears to understand, but insists he is fine.
6. To complete hospital passport (Action: Nursing & Doctor).
   Done
7. Communication passport (Action: Speech & Language Therapist)
   Done. Mr AB is capable of expressing his views clearly. He can be concrete in his understanding and needs reasonable adjustments in the way information is given to him.
8. To offer contact and support with the family (Action: Hospital social worker, Nursing).
   Is estranged from the family and hence has no direct contact with them. Does not want to see an advocate. Has a social worker who is in contact for care planning.
9. Mental Health (Action: Psychology, Doctor, Nursing): Updated formulation and associated additional treatments where practical to address any likely exacerbation of mental health symptoms and/or challenging behaviour (e.g. increase in compulsive checking, handwashing or rituals, increasing demand avoidance and associated aggression)
a. The COVID care plan and/or hospital passport could cover, as needed, issues of diagnostic overshadowing, listening to parents or carers, need for reasonable adjustments, communication, behavioural responses to illness, capacity, specialist mental health support that is available, any end of life or do not attempt cardio-pulmonary resuscitation (DNACPR) discussions that may have happened, as appropriate, etc.

b. **Explain to patients and families**, the precautions around hand washing, the need not to touch their face or eyes as far as possible, the use of tissues while coughing or sneezing and the need to dispose the tissues, the unit’s new protocols about restrictions on visits, the limitations on community leave, precautions adopted in areas where people used to congregate before (e.g: dining rooms, activity rooms, etc.), the processes that will be followed in the event of a suspected case and the need for isolation if there is a suspected case (an ID adapted education package). There are a number of new resources available for these discussions, including one from [Books beyond Words](#).

c. In case of patients deemed not to have the capacity to understand this, have best interest discussions on the procedure that will be followed if isolation is needed. Use technology (e.g.: Skype or equivalent) to facilitate these discussions with carers and families. Please be aware of any LPA (Lasting Power of Attorney) for health and welfare or Court of Protection appointed deputy.

d. **Monitor vital signs** (NEWS) daily for all in-patients and monitor for signs and symptoms of COVID-19 - fever, new cough and other features

**Community contact/ Leave**

- The **stringent social distancing** should, in theory, apply to all those with an intellectual disability because they are at risk of severe illness. For those with intellectual disability and additional conditions that bring them in the extremely vulnerable group at very high risk of severe illness, **shielding measures** should apply, in theory too. Please note however that that this guidance is intended for use in situations where people are ‘living in their own homes’. Hence, these measures may need to be adapted for in-patient psychiatry settings in a person-centred way.
- Avoiding contact with anyone who is showing suspected symptoms, avoiding social contact with others including family or friends, avoiding use of public transport, avoiding
community leave, etc. are reasonable steps. The treating team should use accessible information sources and explain this to the patient group.

- In rare circumstances, there may be a need to consider exceptions. The relevant legislation provides the general prohibition that during the emergency period “no person may leave the place where they are living without reasonable excuse”. It however provides that it is a reasonable excuse to “avoid injury or illness or to escape the risk of harm”. For some people who are rigidly routine bound and prone to extreme outbursts of aggression or self injury when those are changed, there may be a case to have some community trips as a way to escape the risk of harm. This should be an exception rather than the rule and the treating team may need to discuss this carefully with the family and carers. This may change further as government guidance changes.

**Suspected COVID 19 case on the ward**

a. Public Health England has provided guidance on this. Please follow your unit’s operational advice on the assessment process.

**Initial assessment:**

b. Assess patient in a single occupancy room. Current guidance in some organisations, though not all, is that the assessing clinician should wear personal protective equipment (PPE) for all face to face interactions with patients regardless of whether the patient has symptoms of COVID or not. Guidance on this changes frequently and please refer to the Public Health England website for the latest information. At present, as a minimum, this should be a fluid resistant surgical mask, single use disposable apron, gloves and eye protection if blood and or body fluid contamination to the eyes or face is anticipated. A video from Public Health England that shows the donning and doffing procedure is available here.

- It is unlikely that there will be any aerosol generating procedures (AGP) on such assessments. (It has been clarified that spitting is not such an AGP). If a patient meeting the case definition undergoes an aerosol generating procedure (AGP), then a FFP3 respirator, long-sleeved disposable fluid-repellent gown, gloves and eye protection must be worn; in practice, in a psychiatry ward this scenario may arise in a cardio-pulmonary
resuscitation attempt and/or use of suction. Use of CPAP and use of high flow nasal oxygen are also noted as aerosol generating procedures.

**Isolation**

- Follow the unit’s operational advice on isolation of suspected patients.
- As the unit has already discussed this with the patient group, they should be aware of this.
- In case of patients who do not have capacity, follow the best interest decision that has been agreed. This should be recorded along with the capacity assessment in the usual way on PARIS.
- Avoid the need for any restrictive intervention to implement isolation. However, if there are no other alternatives, such interventions may be needed to protect the patient and others.

**Ongoing monitoring**

- Isolation can be a potentially distressing experience and a number of measures to mitigate this are described later in this guidance.
- Isolation is likely to be associated with increasing challenging behaviour, and this will be more marked for those with intellectual disability who have communication difficulties and those with autism.
- Some units have access to COVID-19 testing kits and more may have it soon. If that is available, to send swabs to the designated general hospital for testing to confirm COVID-19. PHE guidance on this states as follows:
  - Following a clinical review of the symptomatic (new persistent cough and/or high temperature) service user after 24-48 hours, if the symptoms have resolved and there are no further cases reported – service users should not be swabbed
  - If symptoms persist and/or there are a number of further cases reported – swabbing to take place
  - Any service user who has reported with symptoms is to continue to be in isolation for 7 days
• Any confirmed COVID-19 cases, to be isolated from 7 days from the date the result was received.
• Continue with daily physical monitoring with NEWS scores being recorded 6 hourly or at a frequency considered appropriate by the medical team.
• Ensure adequate nutrition and hydration and symptomatic treatment as appropriate (Paracetamol for fever, asthma medication as indicated, maintaining fluid intake and urine output charts, etc.)
• Watch for any signs of deterioration. Fever can continue for a few days but respiratory function can worsen between 5-12 days. Potential red flags include
  • Respiratory rate raised over 20
  • Pulse more than 100/minute
  • Struggling to breathe
  • Looking unwell
  • Agitated, confused behavior in an unwell patient
  • Known asthmatic/ COPD patient whose usual dose of inhaler is not relieving symptoms
  • Limited fluid intake and reduced urine output
  • Blue lips/ tip of nose
  • Complaints of pain/ pressure in the chest
  • Non blanching rash
  • Cold, clammy skin

Transfer to general hospital or physical health care on psychiatric ward
• Public Health England has provided guidance on this. This may change with time. Please follow your unit’s operational advice on this process, but be aware of the criteria for transfer as set out below.
• **Patients who meet the following criteria (inpatient definition)** requiring admission to hospital (a hospital practitioner has decided that admission to hospital is required with an expectation that the patient will need to stay at least one night), **AND** have either clinical or radiological evidence of pneumonia
OR acute respiratory distress syndrome,

OR influenza like illness (fever ≥37.8°C and at least one of the following respiratory symptoms, which must be of acute onset: persistent cough (with or without sputum), hoarseness, nasal discharge or congestion, shortness of breath, sore throat, wheezing, sneezing

(Note: Clinicians should consider testing inpatients with new respiratory symptoms or fever without another cause or worsening of a pre-existing respiratory condition).

- Do note that early recognition of the deteriorating patient and referral to general hospital is critical for treatment as patients may present with sepsis, pneumonia and adult respiratory distress syndrome. Those with underlying health conditions (set out in boxes 1 and 2) are more likely to progress to complicated illness.

- A consultant to consultant discussion is appropriate wherever possible. As the COVID-19 situation evolves nationally, this may not always be possible. Please see Box 4 for the points to be covered in a referral discussion to the general hospital.

**BOX 4: Points to be covered in a referral discussion to a general hospital**

1. Patient’s name, age, gender
2. Full diagnosis including physical and mental health (mention any conditions from Box 1 and Box 2)
3. Nature and duration of current symptoms and deterioration
4. Functional ability, capacity, and other relevant information form the COVID care plan and health passport (Clinicians have a responsibility to advocate for the person with an intellectual disability. A person with intellectual disability should not be denied care because of the disability).

5. If there are questions about instruments like the Clinical Frailty Score, please be aware that NICE has made it clear that it should not be applied to people with learning disability when making decisions on critical care. The same should apply to other instruments that do not take into account an individual’s pre-existing intellectual or developmental disability. NICE has stressed the need for an individualized assessment and that is what the referrer should help to provide.

- If the patient is transferred to a general hospital, they should be accompanied by at least one member of staff from the psychiatric ward to provide reassurance and support. (If they are detained under the Mental Health Act, then a Section 17 leave form must be completed and staff must remain with the patient at all times. If the patient is transferred to the general hospital under Section 19 then the general hospital must
ensure that they provide mental health staff to support the patient. At this time, it would be preferable to use Section 17 leave rather than transfer the patient’s detention).

- If the patient is not considered suitable for general hospital, there may be a need for more intense nursing and medical interventions on the psychiatric ward than what is currently provided. This will depend on how the COVID-19 situation evolves regionally and nationally and further guidance, both on equipment and expertise in psychiatric wards may be needed.

**End of Life and DNACPR discussions**

- There is a justifiable anxiety in many quarters that if the COVID-19 pandemic gets worse, people with intellectual and other developmental disabilities will be denied access to the physical healthcare that they deserve. If you find this happens then this must be escalated to the Medical Lead or Clinical Director within your organisation who may be able to advice.

- It is an anxiety which was worsened when the NICE rapid guidelines on access to critical care suggested the use of the Clinical Frailty Score (CFS), an instrument that would have systematically disadvantaged people with an intellectual disability. To its credit, NICE quickly amended the guidelines to make clear that CFS should not be applied to this group.

- The vast majority of people within in-patient units are there because of a deterioration in their mental health or behavior and they have otherwise been leading full and fulfilling lives. Hence, the issue of end of life or DNACPR is not particularly relevant for them but may arise.

- There is however a small group of people in some category 6 and other in-patient services (e.g.: specialist residential service provision in a hospital setting) who are an ageing population with multiple frailties who have suffered a marked deterioration in their adaptive functioning. Likewise, there may be a further group who while relatively healthy now, have a precipitous decline in their physical health once they develop a virulent infection. In the context of COVID-19 or other acute illnesses, there may be a need to consider carefully formulated plans for these groups.
The underlying principles for any such discussion as set out in the document ‘The route to success in end of life care - achieving quality for people with learning disabilities’ are care being client-centred and integrated, individuals being treated with dignity and respect, people’s preferences being identified and respected and care being provided after death. Processes that create personalized recommendations for a person’s clinical care in a future emergency in which they are unable to make or express choices have also been described by the Resuscitation Council in their document Respect. Wherever appropriate, treating teams should use the guidance from these documents to formulate these plans. More guidance on this is expected in the next few days.

RISK TO MENTAL HEALTH

1.8 People with an intellectual disability who are in in-patient settings have considerable psychiatric co-morbidity. For those treated in non-secure hospital settings, they show rates of comorbid major mental illness ranging from 40 to 84%. This is in addition to other comorbid conditions, such as autism spectrum disorders, attention deficit hyperactivity disorder (ADHD), personality disorders and substance misuse. Similarly, high figures are reported for those treated in secure hospital services for people with intellectual disability: up to 50% have a personality disorder, up to 30% have an autism spectrum disorder, about 30–50% have a major mental illness, about 30–50% have substance misuse/dependence and about 20% have epilepsy. Further they are in psychiatric in-patient settings because they invariably have some form of behavior that challenges which may or may not be related to this psychiatric co-morbidity.

1.9 It is perhaps entirely predictable that when faced with an actual or suspected COVID-19 infection and the inevitable restrictions on their activities, there may be an increased risk of worsening mental health symptoms or mental illness relapses and behaviors that challenge.

Assessing and categorizing

1.10 Patients are in an in-patient psychiatric setting because their clinical presentation was above the threshold of what could be managed safely in community settings. Hence if you are using a RAG rating to quantify the patient’s risk of either a worsening of mental
health symptoms or a mental illness relapse, it would be logical to place all in-patients within the Red category. The presence of co-morbidities (ie, other developmental disorders and behavior phenotypes, mental illnesses, substance misuse, personality disorders, past experience of trauma, physical illnesses, etc), the use of medications that need close monitoring (eg: Clozapine), the presence of psychosocial stressors (eg: effect on family visits, community leave, etc) will all help to further quantify and describe the risk factors.

**Proactive interventions**

a. These should run in conjunction with the proactive interventions set out for the risk to physical health.

b. Explain to patients and families, the precautions around hand washing, the need not to touch their face or eyes as far as possible, the use of tissues while coughing or sneezing and the need to dispose the tissues, the unit’s new protocols about restrictions on visits, the limitations on community leave, the processes that will be followed in the event of a suspected case and the need for isolation if there is a suspected case (an ID adapted education package). There are a number of new resources available for these discussions, including one from Books Beyond Words.

c. In case of patients deemed not to have the capacity to understand this in spite of all these efforts, have best interest discussions on the procedure that will be followed if isolation is needed. Use technology (e.g.: Skype or equivalent) to facilitate these discussions with carers and families. Please be aware of any LPA (Lasting Power of Attorney) for health and welfare or Court of Protection appointed deputy.

d. Explain to patients and families changes around the Mental Health Act, Tribunal and Managers’ hearings.

e. Have a range of activities which are shorter duration and deliverable within the hospital ward or units. A range of resources and suggestions are available for this from various agencies.

f. Be aware of the following factors that may cause emotional distress

   • Changes in routine causing increased anxiety, agitation and acting out behaviours. This can be related to difficulties with communication and understanding the changes, as
well as mental health problems, and other associated functions (e.g. demand avoidance, or access to tangibles, including previously enjoyed activities).

- A change in key staff members – the patient’s usual keyworker, named nurse, doctor, therapist may be self-isolating or unwell causing rising anxiety levels and disruption
- The introduction of PPE for all face to face interactions may impact in three ways. Firstly, the face mask will hide important facial expressions which our service users need to assist understanding. Secondly, the mask could also impact on the intelligibility of our speech. Thirdly, the use of PPE could frighten some service users which could lead to a flight/fright response. During these times people are less likely to pick up on communication from others, particularly related to emotions. The following advice may help the interactions between staff and service users.
- Introduce yourself each time you see someone. Use of the staff boards is particularly useful at these times.
- Slow speech down, and increase volume slightly. Try not to shout as this can distort the message
- Say the person’s name before speaking to them. There may not be the visual cues to help them understand you are directing the message to them.
- Keep information very clear and concise – think one piece of information per sentence
- Allow the person time to process what you have said
- Be positive in your communication – tell the person what you would like them to do.
- Your facial expression is limited – try to make your eyes warm and caring as this is the only thing people can properly see
- Use other means to support your message – use natural gesture, write it down, draw it out so the person can see what you are talking about.
- Check back with the person you have a shared understanding. Avoid using ‘do you understand?’ as people will respond positively. Ask ‘what is our plan?’ ‘what have we agreed?’
- Be aware that some service users already struggle with asking for help. This difficulty may increase with the use of PPE. Observe carefully for any changes which could suggest a need for assistance.
g. Do not assume that distress and acting out behaviours are necessarily a relapse of mental illness. Incorporate these and other COVID related mental health risks into the formulation and Behaviour Support Plan which should directly inform psychological and other interventions.

h. Review the psychotropic medication regime and ensure that it is in line with the Royal College of Psychiatrists good practice guidelines and NICE guidelines. In particular, pay attention to the possibility of side effects like respiratory depression and cardiac effects. This may mean a careful analysis of effects and side effects and a considered view about use of psychotropics to maintain good mental health. Also be aware of diagnostic overshadowing- (e.g.: a high fever may well not be due to COVID 19, but related to the rare side effect- Neuroleptic Malignant Syndrome or Serotonin Syndrome).

i. Ensure close liaison with pharmacy services to ensure medication supply to in-patients. At time of discharge, can provide medication for a longer duration – 28 days if that is considered necessary. FP10 prescriptions can be posted via the Royal Mail tracked service to the service users preferred chemist and emailed on nhs net.

j. Carefully monitor the use of restrictive interventions and try to minimize their use as much as possible.

k. Work in conjunction with family members and carers to allay patient anxieties. Encourage alternatives to face to face visits- e.g.: telephone calls, use of Skype, etc. so as to maintain contact.

l. Wherever possible, expedite discharge planning so as to keep in-patient stay to a minimum and reduce other risks. To liaise and flag up to service commissioners, barriers to safe discharge. In keeping with good practice, continue to have Care and Treatment Reviews (CTRs) that can be held with aid of technology.

m. Pay attention to sources that offer information on minimizing health anxiety among service users, carers and professionals.
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