

Guidance to staff on communicating with patients who experience barriers to engaging with us and the people close to their care

Background

- 1 Our usual approach when making enquiries about or investigating a concern about a doctor that is specifically related to the care of an individual patient is to contact the patient to notify them we are investigating and check if they hold relevant information as well as addressing any issues about the use of their sensitive data.
- 2 This guidance deals with communicating with patients who experience barriers to engaging with us, lack capacity to engage with us or who are deceased, to consider contact being made with the person close to the care of the patient to notify them of the investigation and to check if they hold information that may be relevant to our investigation. When we refer to the person close to the care of the patient in this document, we mean the person most involved in the patient's care. This may include, but is not limited to: an appointed power of attorney, their carer, a family member or a close friend.
- 3 This guidance is likely to be useful where:
 - the patient struggles to engage and may lack mental capacity (this includes complaints and referrals and applies to both adults and patients under the age of 16)
 - the patient is deceased, and
 - the concerns have been referred to us by someone acting in a public capacity (eg coroner, Responsible Officer (RO), employer, prison officer) – '**referral cases**' or,
 - the concerns have been brought to us by someone other than the patient or someone close to them but who is not acting in a public capacity including by the doctor who is the subject of the concerns because they have been criticised in the course of an official inquiry – '**non-referral cases**'.

- 4 When concerns are referred by a referrer (ie person acting in a public capacity) about a patient who is deceased or who lacks capacity, the referrer is best placed to notify the person close to their care to let them know that they have raised their concerns and that the GMC may contact them if the concerns are taken further.
- 5 When we contact the patient or the person close to the patient, the purpose is to notify them that we have decided to look into the concerns and to give them an opportunity to provide comments about the incident. If the comments are factual and relevant, a witness statement may be taken. GMC Legal will make this assessment and it is important that where we are likely to require evidence from the patient or the person close to their care this is managed by the Legal Team and not collected on a piecemeal basis through contact with the investigation team.

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Communicating with patients when there are barriers to engaging

- 7** We may encounter difficulties communicating with a patient because of their ability to engage with us. Patients can struggle to engage if they lack mental capacity due to an underlying medical condition or neurological impairment of the brain. When a patient has capacity it means that they have the ability to use and understand information to make a decision, and communicate the decision they have made. Below is a non-exhaustive list of conditions which may cause impairment to the patient's short-term or long-term mental capacity:
- mental health conditions (for example, patients with schizophrenia or bipolar disorder may lack capacity during some periods of their illness)
 - dementia
 - severe learning disabilities
 - brain damage – for example, from a stroke or other brain injury
 - physical or mental conditions that cause confusion, drowsiness or a loss of consciousness including those caused by specific medications
- 8** The law states that a patient's capacity should always be presumed unless there is cogent evidence to confirm that they lack capacity and therefore the list above is not in any way an indicator of capacity. Cases where there is cogent evidence that a patient lacks capacity are likely to be infrequent and may, for example, include circumstances where the patient has been unconscious for a reasonable amount of time and it is unlikely to be temporary or the information in the referral states that they are profoundly disabled and have an appointed attorney to make decisions on their behalf.
- 9** If we receive a complaint from someone who is struggling to engage, we can give them the option of having someone else (such a family member or friend) act on their behalf and receive communications from the GMC. We will need the patient's consent before we make any disclosures to a third party.
- 10** If we don't have consent to contact someone else we can explore other methods of communication to support the needs of the patient. In conversations, the TED technique, which invites the patient to tell, explain, describe what they would like to happen in response to open questions, is a useful tool for initiating discussion.. If this is not possible, or the patient is still struggling to engage, staff should send tailored information about local advocacy services to the patient. Advocates may have specialist knowledge of the patient's condition and be in a position to help the patient communicate with us.

- 11** In circumstances where it is difficult to obtain information from a patient who does not have someone acting on their behalf, we may wish to consider evidence from other possible sources such as witness statements from those present at the time of the incident.

Patients under the age of 16

- 12** If we are looking into concerns about the care provided to a patient under the age of 16 it is highly likely that we would share information with their parental guardian(s). There may be exceptions to this, for example it may not be appropriate to share information with the parents of an older child where the healthcare received relates to choices relating to personal autonomy such as: seeking advice about contraception, abortion, sexual orientation, and gender reassignment. These are examples and there may be other scenarios not listed here. If there is any uncertainty, the Legal Team should be contacted for advice.
- 13** If, having carried out any relevant steps set out above, we believe that a patient lacks capacity to engage with us or where the patient is deceased, guidance is provided below about how to ensure we engage appropriately.

Referral cases

- 14** When we receive a referral we should check if the referrer has indicated that they have contacted the patient or person close to their care. Where the referral contains sensitive data about the patient, they may have done so under data protection legislation. In other cases, where there is no legal obligation to do so they may have done so as a matter of courtesy.
- 15** If they have not already made notification before sharing the concerns with us, we consider that the referrer is best placed to make that notification and we should contact them to discuss whether they would be willing to do so.
- 16** If they are not willing to do so, we should check if contact details have been included with the referral and if not we should ask them to provide contact details.
- 17** We should seek reasons from the referrer if they are not willing to make notification and/or provide contact details (eg unclear who the person close to the care of a deceased patient is due to family disputes, there is an ongoing legal dispute with the trust, the patient was at a mental health outpatient centre and didn't provide their details or if the referring body does not usually treat patients - this may include prisons and governmental bodies).
- 18** All of the known factors both about the patient or the person close to their care and/or any reasons provided by the referrer should be considered when we decide if it is appropriate for us to make direct contact with a person close to the patient's care about the referral.

- 19 Alternatively, the referrer may have contacted this person but indicated that there are reasons why GMC contact is inadvisable (eg the patient or person close to their care is very vulnerable, they have indicated that they do not wish to be contacted etc) we will consider this information when deciding if it is appropriate to make contact.
- 20 If considering direct contact with a patient or person close to the care of the patient, staff should discuss this with an assistant registrar or their manager and record the decision on the case file.
- 21 If the referrer has contacted the patient or the person close to their care and they have not raised any concerns about us contacting them, we should do this during the provisional enquiry or at investigation stage once this is agreed by the assistant registrar or investigation manager.
- 22 The process for contacting the patient or person close to their care is set out below.

Non-referral cases

- 23 When we receive a non-referral case (ie the concerns have been brought to us by someone other than the patient or someone close to them but who is not acting in a public capacity including by the doctor who is the subject of the concerns because they have been criticised in the course of an official inquiry) we should check if the contact details have been provided or if we need to take steps to identify these. The process for this is set out below.

Identifying the contact details for the person close to the care of the patient

- 24 In circumstances where we haven't received contact details from the referrer, or it is a non-referral case, and we have decided to make contact, the most practicable approach to identify the contact details is to look to the information we hold (for example, the contact details may be contained in the referral or in the medical records). Staff should discuss making a potential disclosure with their manager, and record the decision reached.
- 25 If we are unable to identify the person close to their care from the information we hold we may consider contacting another source to get this information (eg this may be held by the incident location RO or the patient's primary care provider). Staff should discuss whether it is appropriate to request this information with their manager.
- 26 We should explain to the person we write to that we are seeking contact details for the person most involved in the patient's care and/or who attended appointments with them (for example, this may be recorded as the next of kin, emergency contact, carer or power of attorney).

Concerns that arise during an existing fitness to practise case

- 27** In some circumstances, we may receive concerns relating to the care of a patient who is unable to engage either during an investigation or post rule 8, prior to a hearing. If those concerns amount to an allegation of impairment then we should also consider if it is appropriate to contact the person close to the patient. We should check if the contact details have been provided for the person close to their care or if we need to take steps to identify these (see above).

Communicating with the person close to the care of the patient at provisional enquiry stage

- 28** Once the assistant registrar has decided to look into allegations as a provisional enquiry they should also determine if it is appropriate to write to the person close to the care of the patient to let them know and, if so, when.
- 29** In making the decision to write to the person close to the patient's care, the assistant registrar must consider how substantive the evidence we hold and how confident we are that the matter engages our procedures. On the basis of this consideration, the assistant registrar at provisional enquiries stage may decide to contact the patient or the person close to their care:
- At the onset of a provisional enquiry
 - Once we have received further information through the provisional enquiry process that supports that our threshold is engaged
- 30** If, after further enquiries, we decide that we are not confident that our thresholds are met we may decide not to communicate with the person close to the care of the patient.

Communicating with the person close to the care of the patient during an investigation

- 31** At investigation stage we may decide to write to the person close to the care of the patient if it has been identified that the patient is unable to engage with the investigation (ie because they are deceased or lack capacity). We would normally make this disclosure at the outset of an investigation. This decision will be made by staff investigating the concerns after discussion with their manager.

Concerns that relate to a number of patients

- 32** If the concerns raised about a doctor relate to a number of patients, we often may not seek to contact the patients and therefore we also may often not seek to contact

the person close to any patients who are deceased or who lack capacity at the onset of the investigation. In the interest of managing the expectations of patient families, the disclosure will be kept under review and reconsidered once we know that a specific patient's care forms part of the investigation (for example the point at which we are obtaining an expert report). In some cases we may decide to invite the doctor to undergo a performance assessment and, where this occurs, we are less likely to contact the person close to the care of the patient because the concerns about a doctor's performance are being assessed in the round, and not against the standard of care provided to individual patients.

- 33** Where we conclude it is appropriate to contact the person close to the care of the patient, we will ask the person acting in a public capacity to provide us with their contact details for each relevant patient when we make a decision about taking specific concerns forward, if they haven't been provided already.
- 34** If the referrer has recommended that we do not contact one or all of the people close to patients' care then we should consider if it is appropriate for us to do so.
- 35** If the referrer does not have the contact details for the people close to their care we should consider whether to try to access them from details that we hold.

Information to disclose to the person close to care of the patient

- 36** Once we have decided to make a disclosure to the person close to the care to the patient, staff should write to the doctor under investigation to notify them that, as part of our enquiries into the care provided to a: deceased patient; patient under the age of 16; or a patient who lacks capacity, we may write to the person closest to their care and ask if they hold relevant information and give them an opportunity to make comments about the patient's care. We should advise the doctor that if the person close to the care of the patient makes comments that are relevant to our investigation and factual in nature, it may be recorded as witness evidence in a full investigation.
- 37** Our initial contact to the person close to the care of the patient to let them know that we are looking into concerns should be carefully managed. As we will not have been able to verify the contact details provided to us for the person close to the care of the patient, the first letter should be a pathfinder letter to ensure that correspondence is not directed to the wrong address, and to limit the amount of information we share at this early stage. Once we have opened a dialogue with the person we write to and they confirm they are the correct recipient, and would like to be involved in our processes, an assessment should be made about what information we share with them.

- 38** Generally we will disclose a summary of the concerns including the doctor's name, the period of care the concerns relate to and the location of the incident (eg hospital, GP surgery) when we invite the person close to the care of the patient to make comments. It is important that we only share the information that is necessary to carry out our role ie the information that is needed to notify the person about the relevant issues and for them to provide any comments to us about the matters in question. We may receive information from the referrer, the doctor or other sources which suggests that it may not be appropriate to make a disclosure to the person close to the care of the patient or to contact them.
- 39** Factors to consider before disclosing information include:
- Information that suggests that the person has been aggressive towards the doctor (including allegations of threats or stalking)
 - The patient or person closest to the care of the patient has advised the referrer that they don't wish to be involved in the investigation
 - Representations made by the doctor about disclosure to the person close to the care of the patient suggesting that there would be an unjustified interference to the doctor's right to private and family life

If staff are unsure about making a disclosure, they should raise the decision with their Assistant Registrar.

Recording the person close to the care of the patient as an interested party and keeping them updated

- 40** If the person close to the care of the patient confirms that they'd like to be kept updated, and we have disclosed the doctor's name to them, they will become an interested party and contacted about the progress and overarching decision outcome of the case. If the person close to the care of the patient is not an interested party, because we decided not to disclose the doctor's name to them, they will be saved as a patient contact with limited disclosure on our records and sent general updates to avoid breaches of information security.

Recording the person close to the patient as a witness

- 41** The person close to the patient should be recorded as a witness if, after reviewing the initial comments they provide, we decide to take a witness statement from them. Any further disclosures of information about the case, which have not been made already (eg the name of the doctor under investigation and updates about the case), can be disclosed to witnesses under Rule 7(2) of the Fitness to Practise Rules (2004). If the person close to the patient makes comments to investigation staff about their recollection of events during the investigation, they must be referred to the Legal

Team who will arrange to record a formal statement and further contact should be via the Legal Team. This is to ensure that any information about the patient's care can be used as admissible evidence in our processes.

Support available for the person close to the care of the patient

- 42** Some people we contact may need additional support including if they are bereaved or vulnerable. Staff should signpost vulnerable people to organisations which may be able to help them. [The FPT complainant signposting guide](#) has a list of organisations covering a number of support specialisms including grief and bereavement. The witness support service can be accessed by patients or witnesses of fact involved in a full GMC investigation. The service is run independently by Victim Support to give free and confidential emotional support. You can arrange for them to contact the complainant or they can contact them directly by phone 0161 200 1956 or email witnesssupport@gmc-uk.org.
- 43** The person close to the care of a patient may benefit from a meeting with the patient liaison service to help them understand our investigation process. Staff should raise potentially suitable cases of this type with the patient liaison service to consider an offer of a meeting prior to mentioning this service to the person close to the care of the patient. The patient liaison service will assess the case to ensure that meetings will only take place in circumstances that enhance the customer service experience of the person closest to the care of the patient.