Discussing healthcare associated infection (HCAI) and specific antimicrobial resistant organisms (AMROs) with patients[1] who may have acquired a HCAI, become colonised with an AMRO or been exposed to a specific HCAI/AMR risk

CPE Expert Group

National Guidance Document, Version 1.0

Scope of this Guidance

This guidance is intended for healthcare workers providing patients with information related to a healthcare associated infection (HCAI) and/or antimicrobial resistant organisms (AMROs). For further information on the scope of this guidance, refer to page 4 of this document. For additional guidance or to confirm that you are using the most current version of this guidance, please go to www.hse.ie/hcai and www.hpsc.ie

Next review of this guidance document

This guidance document will be reviewed in 12 months (July, 2019).

1 In some cases communication will involve parents, carers, family or other relevant person(s). "Relevant person(s)" means a person who is a parent, guardian, son or daughter a spouse, or a civil partner (within the meaning of the Act of 2010), of the patient, a person who is cohabiting with the patient (including a cohabitant within the meaning of Part 15 of the Act of 2010), or a person whom the patient has nominated in writing to the health services provider as a person to whom clinical information in relation to the patient may be disclosed.

Table of Contents

Abbreviations/acronyms

AMRO = Antimicrobial resistant organisms

CPE = Carbapenemase producing *Enterobacterales*

ESBL = Extended-spectrum beta-lactamase producing Enterobacterales

GP = General practitioner

HCAI = Healthcare associated infection

HSE = Health Service Executive

IPC = Infection prevention and control

IPCT = Infection prevention and control team

MDRO = Multidrug resistant organism

MRSA = Methicillin resistant *Staphylococcus aureus*

VRE = Vancomycin-resistant enterococci

Scope

This document is intended to support healthcare workers in

- Providing patients with information related to a healthcare associated infection (HCAI) and/or antimicrobial resistant organisms (AMRO).
- Providing patients with information in a manner that respects their right to know about and be involved in their own healthcare.
- Providing patients with information in a manner that respects their rights to privacy and confidentiality. Where appropriate, the communication should meet the requirements of the Health Service Executive (HSE) National Open Disclosure Policy.

The HSE open disclosure process refers to an open and consistent approach to communicating with patients following adverse events in healthcare. An adverse event refers to an incident where a patient has suffered harm which may or may not be as a result of an error or failure in the delivery of care.

It is important to recognise that the development of a HCAI by a patient or the detection of an AMRO in a sample from a patient does not mean that there has been a breach of safety procedures or error in care. HCAIs occur in every country, even with optimal practice. In all cases, however, there should be appropriate clinical communication to inform the patient. Where there is an identified breach of a safety process or an error in care, the communication process will generally involve the patient's clinical team, but in many/most cases it will also involve Clinical Directors, Directors of Nursing and Hospital General Managers/CEOs.

This document should be read in conjunction with the HSE National Open Disclosure Policy and Guidelines which provide the detail in relation to managing open disclosure discussions. These documents are available on www.opendisclosure.ie or www.hse.ie/opendisclosure.

The effective implementation of this policy requires leadership, adequate training and support for staff in relation to communication skills, HCAI, AMRO and the Open Disclosure process. Protected time to engage with patients is a key part of the support needed for effective implementation.

Definitions

Healthcare associated infection (HCAI) refers to harm to service users/patients as a result of acquiring an infection when receiving healthcare due to the process of healthcare delivery (HSE Corporate Risk Register).

Antimicrobial resistance is harm to service users/patients due to the emergence and spread of AMROs (for example, Carbapenemase producing Enterobacterales (CPE)) through contact with the healthcare services (HSE Corporate Risk Register).

Antimicrobial resistant organisms (AMROs) are bacteria that are resistant to antimicrobials that bacteria of that species are normally expected to be susceptible to and which are important for therapeutic purposes.

Open disclosure is defined as an open, consistent approach to communicating with patients following adverse events in healthcare. This includes expressing regret for what has occurred, keeping the patient informed, providing feedback on investigations and actions taken to prevent a recurrence (HSE Open Disclosure Policy, 2013).

An adverse event is defined as "*an incident which resulted in harm that may or may not be the result of error"* (HSE Incident Management Framework, 2018).

The AMROs of concern here are those that have implications for infection prevention and control (IPC) or therapeutic purposes, such as methicillin-resistant *Staphylococcus aureus* (MRSA), vancomycin-resistant enterococci (VRE), extended-spectrum beta-lactamase (ESBL) producing Enterobacterales, *CPE* or other multidrug resistant organisms (MDROs). Designation of bacteria as a MDRO is normally made by the IPC team (IPCT) and the diagnostic microbiology laboratory.

Background

The HSE promotes a culture of openness and transparency in all health and social care services. This applies to HCAI and AMROs. The risk of a HCAI cannot be eliminated entirely. A HCAI may be caused by the patient's own microorganisms (endogenous infection) or may be due to microorganisms that were picked up in the healthcare setting (exogenous/cross infection). The number of people who contract a HCAI can be reduced by the way in which healthcare services are organised and delivered, and by the consistent application of IPC practice. In some, but not all circumstances, HCAI or the acquisition of AMROs may be clearly related to identifiable errors/omissions in relation to the organisation or delivery of healthcare.

General Information for Patients

All healthcare service providers should ensure that patients and visitors are informed that there is a particular risk of exposure to AMROs and infection in healthcare settings. Patients and visitors should be advised how they can minimise the risk, for example through hand hygiene, limiting physical contact with other patients, generally keeping away from other patients' bed space, and advising a staff member promptly if they note shortcomings in relation to hygiene, especially in toilet and bathing areas. Informing patients/visitors of this risk from the outset may prepare patients for the communication process involved if a specific exposure is recognised.

Appendix 1 outlines in general terms information about these risks that should be provided to all patients on admission to an acute hospital.

Appendix 2 outlines in general terms information about these risks that should be provided to all patients when leaving an acute hospital.

Exposure to HCAI/AMRO: When is specific targeted communication required?

The following situations clearly require direct targeted communication to the person concerned:

- There is a specific exposure that requires a specific drug treatment (for example, exposure to influenza virus in a setting where prophylaxis with oseltamivir is recommended).

- There is a specific exposure that requires specific follow-up testing at any time (for example, swabs to test for colonisation).

- There is a specific exposure that requires any specific measures for containment on subsequent representation to an acute hospital (single room isolation) or that may impact on the patient's access to healthcare.

IMPORTANT

The general information reflected in Appendix 1 and Appendix 2 is **not** sufficient in the situations outlined above.

Why is it important to tell patients about HCAI and AMRO?

Patients have a right to information in relation to their healthcare: It is their information and the patient is the person with the greatest vested interest in the outcome of their health care. Some of the distress and anxiety for patients with HCAI/AMRO or with a specific exposure to HCAI/AMRO risk can be minimised or even avoided if they are fully informed at an early stage of the implications and about any testing or treatment involved. When patients find out through a secondary or tertiary source that they have a HCAI/AMRO, or have been exposed to a HCAI/AMRO, it can cause them undue alarm and distress and also undermines their trust in the healthcare system and in healthcare workers.

Patients do not always experience seamless continuity of care and they have a major role to play in relation to information sharing and their own safety. Having information about their health empowers patients to play this role. Therefore patients should be informed as fully as possible and as soon as is reasonably practical in the context of their overall condition, if they have a HCAI, if they are detected as colonised or infected with any AMRO of specific concern, or if they are known to have had a specific exposure to a particular HCAI/AMRO risk (that is to say they have been designated as “contacts”).

Whenever possible the patient should be informed face-to-face in a clear and open manner by a doctor or nurse from the patient’s own clinical team. This communication should happen as soon as is practical taking account of the patient’s current location and condition. If the patient has already gone home it may take longer to organise the communication and the form of the communication may be different. Patients may not fully take on board all the information the first time they hear it and they should be provided with further opportunities to raise concerns.

Managing the discussion of HCAI/AMRO with patients and their family/relevant person(s)

The following principles must apply when informing patients and their family/relevant person(s) of their HCAI/AMRO status:

1. Responsibility for the Communication.

In hospitals, it is the primary duty of the Consultant responsible for the patient's care to inform the patient or to ensure that they are informed by an appropriate person. The initial communication may be followed up by a visit from a member of the IPCT if requested by the Consultant or the patient.

In the community when the General Practitioner (GP) receives correspondence regarding a HCAI/AMRO, the GP should seek to determine if the patient is already aware of the issue. If the infection was acquired in, or the exposure occurred in a hospital setting, it is primarily the hospital's responsibility to ensure that the patient is informed of this. Likewise if a laboratory test that identified the issue of concern was submitted by a member of the hospital staff it is primarily the hospital's responsibility to ensure that the patient is informed of this. In some cases the GP may undertake to facilitate that process of communication between hospital and patient. In that event, the hospital should confirm with the GP that the communication has occurred. In all cases the GP should be informed of communication from the hospital to the patient.

2. Planning the Communication

Receiving this information may be upsetting for the patient and therefore the information should be delivered in a sensitive and empathetic manner and in an appropriately private setting.

IMPORTANT

Ensure that every effort is made to protect the privacy of the patient and to maintain her/his right to confidentiality. Delivering this information in a shared space behind a curtain where other patients can hear the details must be avoided.

3. Encouraging the patient to have a support person present

4. Ensuring that an interpreter is present if required

5. Know the facts

Before talking to the patient the clinician dealing with the communication should make sure that they have established the facts available in relation to the HCAI/AMRO or exposure incident. In the acute hospital sector support and advice is generally available from a member of the IPCT.

6. The Communication

Tell the patient the facts, provide a clear explanation in simple and non-technical language, and acknowledge any impact or potential impact for the patient. Clarify any matters that may cause confusion for them such as the difference between “colonisation” and “infection” and confirm their understanding by asking them to feedback their understanding of what they have been told. Acknowledge any failures in the delivery of care and express regret and apologise as appropriate.

Provide the patient with a Patient Information Leaflet or access to other materials (such as websites) to support their understanding. The content of the leaflet or other information source should have been developed at national level or if locally generated must be consistent with national guidance where available. A copy of the leaflet must be inserted into the patient’s notes or record, and the date, time and communication of diagnosis by the healthcare professional recorded. Leaflets in languages other than English should be used as appropriate.

Address any questions the patient may have and discuss, with their input, plans for their future care. Provide reassurance in relation to ongoing treatment/care/further screening etc. Provide relevant further information via patient information leaflets and also information regarding relevant support groups, if appropriate.

When conveying any information on HCAI/AMRO status or exposure, the doctor or nurse should be supported by other healthcare workers as required.

7. Follow up on the Communication

Patients may not fully take on board all of the information provided at this first meeting and they should be provided with further opportunities to ask questions or to talk about their concerns.

In hospitals the AMRO status of the patient must be permanently recorded by tagging/labelling the patient's notes and/or by indicating this also on the hospital IT system or equivalent. This must be done in a sensitive manner. For example, the label or electronic tag could indicate "infection risk", rather than explicitly stating "AMRO (name of AMRO) positive".

Some form of record of a positive AMRO status that is easily disguisable should also be maintained in the community or in GP surgeries, and on the current set of notes being used in the community, in residential units and GP practices.

The patient should be informed of any tagging/labelling which has been applied to their notes and the reasons for this should be explained to them.

The nursing and medical notes in hospital and patient record/notes outside hospital must indicate the care plan for the patient with regard to management of the patient. This should take account of relevant national or international guidance.

Given that there is not a single national patient record, consideration should be given to providing the patient with some form of durable and portable aid (for example, a plastic card) to support them in informing healthcare service providers of their AMRO colonisation/contact status, when they seek care from a different health service provider.

When the patient is being discharged to the care of his/her GP, or when the patient is being transferred to another hospital, community unit or nursing home for further care, the HCAI/AMRO status of the patient **must** be notified to the receiving carer.

Disclosure of information to family members/relevant person(s) in relation to adult patients should only be undertaken with the consent of the patient. When the patient does not have the capacity to provide consent the decision to disclose information to family members/relevant person(s) should be made by the most responsible person involved in the care of the patient (for example, a doctor caring for the patient). This decision should take into consideration (i) what information is deemed appropriate and justifiable to share and (ii) any known preference or instruction provided by the patient in relation to the sharing of their information. The information provided to family members/relevant person(s) should include only the necessary information relating to the given situation.

The HSE policy requires that the salient points of the Open Disclosure discussion including the details of any apology provided and details of agreed actions are documented in the patient's clinical/nursing records.

Supporting staff to effectively communicate with patients about HCAI/AMRO

One of the barriers to informing patients about HCAI/AMRO or exposure to specific risk of HCAI/AMRO is the lack of confidence of some staff in their ability to answer the questions that patients may have in relation to HCAI/AMRO. Healthcare workers must be supported with access to appropriate information and training. This support should include access to infection prevention and control practitioners. After initial communication with the patient it may be appropriate to arrange for the patient to meet with an IPC practitioner/member of the IPCT to discuss any further issues.

Staff should be provided with an opportunity to access Open Disclosure training.
Staff should be made aware of the protective legal provisions for staff in Part 4 of the Civil Liability Amendment Act 2017 in relation to engaging in Open Disclosure discussions with patients and their families/relevant persons.

For full details of the provisions of the Civil Liability Amendment Act 2017 visit http://www.oireachtas.ie/documents/bills28/acts/2017/a3017.pdf

Challenges in communicating with discharged patients

There are particular challenges relating to timely and appropriately delivered communication for the patient who has already left the hospital by the time the issue related to HCAI/AMRO becomes apparent. It may happen that evidence of a specific exposure only becomes apparent after the patient has been discharged. It may happen that a result of a microbiological sample indicating that a patient has colonisation with an AMRO may be received from the laboratory after the patient has gone home or left the hospital after an out-patient or emergency department (ED) attendance.

In the event that the colonisation/exposure requires immediate action to prevent or minimise risk/harm to the patient, the situation must be managed immediately through contact with the patient or the patient's GP as appropriate.

While healthcare workers in other settings can play an important part in communicating information to patients after discharge it is primarily the responsibility of the practitioner responsible for requesting and submitting the sample from which an AMRO was first detected and the hospital/facility where an exposure occurred, to ensure that that patient is informed. Likewise where a specific exposure event resulting in the patient being identified as a contact has occurred it is primarily the responsibility of the practitioner with lead responsibility for the care of the patient when they were an inpatient to ensure that that patient is informed.

Where a patient has confirmed infection/colonisation but has left the hospital

1. **Patient is in another hospital or residential healthcare facility**

   The staff in the hospital where the colonisation/infection has been detected should promptly provide the relevant information to the staff of the hospital/healthcare facility where the patient is currently cared for.

   The staff in the facility where the patient is currently cared for may undertake to inform the patient face-to-face in accordance with the principles outlined in this document. If the staff can't do this for any reason they should inform the original hospital which must make alternative arrangements.

2. **Patient is due to attend the hospital in the near future (within one month) and the communication is not urgent**

   It may be appropriate to manage the communication at the scheduled appointment/attendance, that is to wait until the patient is next due to be seen, given the relatively short time period.

   In the event that the next hospital attendance is an unplanned attendance for emergency care the timing and management of the communication must take account of the patient's condition at the time of presentation to the hospital.

3. Patient is not due to attend at the hospital in the near future

The hospital should offer the patient a review appointment at the hospital within one month to facilitate direct communication or arrange for face-to-face communication through the patient's GP if that is appropriate and if the GP agrees to undertake this. If the appointment is at the hospital it should normally be with the clinical team at the hospital who were caring for the patient when the specimen that confirmed a HCAI or AMRO colonisation was taken. The convenience of the patient in relation to access to the hospital should be the primary consideration in choosing which option to apply.

4. Patient is deceased

No communication is required unless the carers /family are considered to be at specific risk, or where there has been an error or omission in relation to care of the deceased patient, or where it may have contributed to the patient's death.

Patient is designated a "contact" (i.e. has had specific exposure to HCAI/AMRO risk) but has left hospital

1. Patient is in another hospital or residential healthcare facility

The staff in the hospital where the exposure occurred should quickly provide the relevant information to the staff of the hospital/healthcare facility where the patient is currently cared for.

The staff in the facility where the patient is currently cared for may undertake to inform the patient face-to-face in accordance with the principles outlined in this document. If the staff in the facility where the patient is located are unable to undertake this for any reason they should inform the original hospital which must make alternative arrangements to communicate this information.

2. Patient is in the community

The patient may be informed by letter. The sender should put in place a process to ensure that the letter is received. The letter should tell the patient where they can get more information and support if they have questions.

NOTE

One consequence of communication with respect to specific exposure to AMRO risk is that it is likely that some patients will request testing for colonisation in circumstances where this is not currently required or recommended in national guidelines. In such circumstances, the patient should have an opportunity to discuss their concerns with a healthcare worker and in general if the patient expresses a clear wish to be tested, this should be facilitated.

Conclusions

It is in everybody's interest to ensure that all patients who develop HCAI, who are colonised/ infected with an AMRO or who are exposed to a specific HCAI/AMRO risk are informed of this as early as possible. The above HSE guidance is designed to ensure a consistent approach.

It is accepted that there may be some local adaptation to particular circumstances or for specific patients provided the core principles are adhered to. While acquiring an HCAI/AMRO or exposure to HCAI/AMRO risk is unwelcome and may cause distress to patients, early communication is in the best interests of the patient, the healthcare worker and the healthcare service.

Frank and prompt communication, with due regard to the privacy and confidentiality of the patient, is likely to allay the fears and anxiety of all concerned. It also allows the patient to become an active participant in his/her healthcare journey and ongoing safety and welfare.

Additional information may be found at www.hpsc.ie and www.hse.ie/hcai:

http://www.hpsc.ie/a-z/microbiologyantimicrobialresistance/infectioncontrolandhai/

http://www.hpsc.ie/a-z/microbiologyantimicrobialresistance/strategyforthecontrolofantimicrobialresistanceirelandsari/carbapenemresistantenterobacteriaceaecre/guidanceandpublications/

https://www.hse.ie/eng/about/who/healthwellbeing/our-priority-programmes/hcai/resources/cpe/

Appendix 1

Example of information leaflet to be provided to all patients at admission to an acute hospital

Risks of Infection in Hospital

Any patient in any hospital is at risk of picking up a new infection in hospital or of picking up an antibiotic resistant bug (a superbug) while in hospital. In this hospital we take care to keep this risk as low as we can by providing you with clean safe care. We do this by following rules about cleaning our hands and by trying to keep everything we use clean. If we know that a patient is carrying a superbug we do what we can to give that person their own space so that the bug does not spread to other patients. We also test a lot of patients to check if they carry superbugs so that we can give them special care if they do carry superbugs. In testing for superbugs we may need to ask you if we can take a swab from your nose, skin or back passage. All of this is to help to keep you safe but it is not possible to guarantee this.

These are some things you can do to help protect yourself from picking up an infection or superbug in hospital:

- Do not share your own things with other patients
- Do not to go into the bed space of other patients (in other words, keep away from other patients' beds)
- Feel free to remind any of our staff to wash their hands or perform hand hygiene
- If you see anything that is not clean, please tell one of the staff

If we find that you have been or are carrying a superbug while you are in hospital we will tell you about it and provide information for you. If we find that you have been exposed to a superbug that might be a risk to you through your contact with another patient we will tell you and we may want to do tests to see if you also have the superbug.

Sometimes we do not find out that you are carrying a superbug or that you shared space with someone carrying a superbug until after you have gone home. If that happens we will arrange to tell you at a follow up appointment, or through your GP or by letter. If you have any questions about hospital infection or superbugs please ask your doctor or nurse.

Signed:

Appendix 2

Example of information leaflet to be provided to all patients on discharge from an acute hospital

Risks of Infection in Hospital

We hope that you are satisfied with our efforts to provide clean and safe care to you during your stay in hospital. If we found out while you were in hospital that you have a superbug or that you have had close contact with someone carrying a superbug your doctor or nurse should have already talked to you about that.

Sometimes a test result can come back after you have left the hospital that shows you have a superbug or that someone you had close contact with was carrying a superbug. If that happens we will contact you to let you know. We will arrange to tell you at a follow up appointment, through your GP or by letter.

Appendix 3

Template letter to inform patients that they have had contact with CPE

At present the issue of designating AMRO contacts arises most commonly in relation to CPE. Correspondence that is generally consistent with the following may be used to inform patients that they have been exposed to a specific organism and have been designated as a contact.

Dear

I am writing to you to about something that happened during your stay in XXXXX Hospital from DATE to DATE. Following your discharge from hospital, a laboratory test result showed that another patient that you had close contact with was carrying a type of antibiotic resistant bacteria (superbug). The bug is called Carbapenemase producing Enterobacterales or CPE for short. Tests show that most people who have contact with a person with the CPE bug do not catch it from them. However, a small number of people in contact with CPE do catch it so there is a chance that you might have picked up CPE.

Based on the information we have from scientific studies, the chance that you are carrying CPE is about a 1 in 20 (5%) to a 1 in 10 (10%) chance.

If you have picked up CPE it is most unlikely that you will feel sick. Most people who have CPE do not ever become ill as a result. We know that about 1 in 40 people who carry CPE may develop a serious CPE infection at some time. The only way to know if you have CPE is to have laboratory tests carried out. The tests are usually done on specimens of faeces (poo) or a swab taken from the rectum (back passage). These tests are recommended for people in an acute hospital but are not usually recommended for other people.

If at some time in the future you are admitted as an in-patient to an acute hospital it is recommend that you have these tests done at that time. A note has been entered on your medical records in this hospital to remind the hospital staff to offer you this test if you are admitted as an inpatient to this hospital in the future. You will be asked if it is OK to carry out the tests. If you do not want to be tested you can say so.

If you are admitted to this or any hospital in the future please tell the nurses and doctors about this letter. To help you to remember, I have provided a small plastic card with this letter. You can carry this card in your purse or wallet. If you show this card to hospital staff it will prompt them to offer you the screening tests for CPE as outlined above.

You do not need any treatment or medicine because you had contact with CPE. You are not required to attend any special clinics. You will only need the screening tests for CPE if you are admitted again to this hospital or another hospital. If you would like to have these tests done sooner rather than later so that you can find out if you are carrying CPE, please contact this hospital and we can arrange for you to speak to someone and to organise the necessary screening tests for you if you wish (add contact details).

If the tests show that you are carrying CPE there is no need for any treatment, but doctors and nurses will take extra precautions in your care if you are admitted to hospital in the future.

We try to control the spread of CPE in the hospital but we do not always know who has and who does not have CPE. There is no way at the moment to make sure that the risk can be completely avoided.

I appreciate that this may be worrying for you. If you require additional information on CPE please visit our website at www.hse.ie/hcai (Enclose an information leaflet and or frequently asked questions leaflet.) Alternatively you can call the hospital at the number below and we will arrange for someone to talk with you.

Yours etc.

Document Type	Guidance	Document developed by	HSE HCAI/AMR Clinical Programme and reviewed by the CPE Expert Group
Approval Date	02/07/2018	Document author	HCAI/AMR Team
Document reference number	Final. Version 1.0	Document approved by	CPE Expert Group
Revision number		Responsibility for implementation	All HSE funded acute hospitals
Revision Date	July 2019	Responsibility for review	CPE Expert Group
Draft or Final document	Final document		