Surveillance proposal consultation document

2021 surveillance of patient experience in adult NHS services (NICE guideline GG138)

1 Surveillance proposal

We propose to not update the guideline on patient experience in adult NHS services.

1.1 Reasons for the proposal to not update the guideline

No update is proposed for all areas of the guideline. There was limited new evidence and new evidence generally supported existing recommendations. In addition, the themes of patient experience that are covered by the guideline are generic and do not change rapidly over time.

Recommendations 1.5.20 to 1.5.27 were not included within the current surveillance review as they have been replaced by NICE's guideline on shared decision making.

For further details and a summary of all evidence identified in surveillance, see appendix A below.

2 Overview of 2021 surveillance methods

NICE’s surveillance team checked whether recommendations in patient experience in adult NHS services (NICE guideline CG138) remain up to date.

The surveillance review of CG138 started in 2019 but was paused in March 2020 when efforts were focused on developing COVID-19 rapid guidelines in response to the pandemic. The review of CG138 resumed in January 2021.

The surveillance process consisted of:

- Feedback from topic experts via a questionnaire.
- A search for new or updated Cochrane reviews and national policy.
- Consideration of evidence from previous surveillance.
- Examining related NICE guidance and quality standards and National Institute for Health Research (NIHR) signals or alerts.
- A search for ongoing research.
- Examining the NICE event tracker for relevant ongoing and published events.
- Literature searches to identify relevant evidence.

- Assessing the new evidence against current recommendations to determine whether or not to update sections of the guideline, or the whole guideline.
- Consulting on the proposal with stakeholders (this document).

For further details about the process and the possible update decisions that are available, see ensuring that published guidelines are current and accurate in developing NICE guidelines: the manual.

2.1 Intelligence gathered during surveillance

2.1.1 Views of topic experts

We considered the views of topic experts who were recruited to the NICE Centre for Guidelines Expert Advisers Panel to represent their specialty. For this surveillance review, topic experts completed a questionnaire about developments in evidence, policy and services related to the guideline.

We received 9 responses questionnaire responses from experts which included 4 consultant physicians, 2 consultant surgeons, 2 specialist nurses, 1 pharmacist and a professor of patient involvement.

Five topic experts thought the guideline should be updated and 4 experts identified that it should not be updated.

The main reasons for indicating the guideline should be updated related to specific points which are discussed in appendix A. Reasons included the following points:

- Broaden the patient independence recommendation to cover a greater scope of settings such as custodial or secure patient environments.
- Offer patients NHS online feedback to improve patient experience.
- Highlight the importance of care records within acute and primary services and the need for shared care records across health providers to improve continuity of care.
- Highlight the role of new technologies in providing information, communication and gathering views.
- Offer specific guidance on patient experience for older people.

2.2 Evidence considered in surveillance

2.2.1 Search and selection strategy

We searched for new evidence related to the whole guideline.

We found 18 studies in a search for systematic reviews between January 2016 and January 2021.

We also included:

- 9 studies identified by searches in an Evidence Update (2014) and previous surveillance (2016).

From all sources, we considered 27 studies to be relevant to the guideline.

See Appendix A for details of all evidence considered, and references.

2.2.2 Ongoing research

We checked for relevant ongoing research; of the ongoing studies identified, 1 study was assessed as having the potential to change recommendations. Therefore, we plan to check the publication status regularly and evaluate the impact of the results on current recommendations as quickly as possible. The study is:

- Improving the safety and continuity of medicines management at care transitions.

2.3 Equalities

Two equalities issues were identified during the surveillance process, both highlighted by topic experts. They concern the need for specific guidance on patient experience for older people and guidance to cover custodial or secure patient environment settings. These issues are discussed in appendix A.

2.4 Overall surveillance proposal

After considering all evidence and other intelligence and the impact on current recommendations, we propose that no update is necessary.

3 Appendix A: Summary of evidence from surveillance

2021 surveillance of patient experience in adult NHS services (2012) NICE guideline CG138

Studies identified in searches are summarised from the information presented in their abstracts.

Feedback from topic experts was considered alongside the evidence to reach a view on the need to update each section of the guideline.

Evidence from an Evidence Update (2014) and previous surveillance (2016) for this topic was also considered. Evidence updates were produced by NICE to highlight new evidence relating to published NICE guidelines.

3.1 Knowing the patient as an individual

3.1.1 Surveillance proposal

No new information was identified at any surveillance review time-point.

The recommendations in this section of the guideline should not be updated.

3.2 Essential requirements of care

3.2.1 Surveillance proposal

The recommendations in this section of the guideline should not be updated.

3.2.1.1 Previous surveillance summary

In previous surveillance of this guideline evidence included 1 systematic review (Larsen & Uhrenfeldt, 2013) covering nutrition and 1 systematic review (Dy et al., 2012) covering requirements of palliative care.

3.2.1.2 2021 surveillance summary

No relevant evidence was identified.

3.2.1.3 Intelligence gathering

3.2.1.3.1 Patient independence

Topic expert feedback suggested broadening the patient independence recommendation to cover a greater scope of settings such as custodial or secure patient environments. On considering this matter we reflected that these recommendations could equally apply to adult NHS services in secure settings, subject to specific constraints of those environments. In addition, consideration of specific patient groups is covered across the NICE guideline suite, including separate NICE guidelines on physical health of people in prison and mental health of adults in contact with the criminal justice system. Mental healthcare and related secure psychiatric hospitals is outside of the scope of the current guideline.

3.2.1.3.2 Pain management

Topic expert feedback indicated the need to update the pain management recommendations in line with the NICE guidance on chronic pain in over 16s. We will add a link from the CG138 NICE pathway to the NICE guidance on chronic pain in over 16s.

3.2.1.4 Impact statement

Overall, the evidence identified through previous surveillance was considered to be consistent with current recommendations on essential requirements of care. No new evidence was identified through the current surveillance to change this conclusion.

3.3 Tailoring healthcare services for each patient

3.3.1 Surveillance proposal

The recommendations in this section of the guideline should not be updated.

3.3.1.1 Previous surveillance summary

In previous surveillance of this guideline evidence included 1 Cochrane systematic review (Dwamena et al., 2012) covering training providers to deliver patient-centred consultations and 1 systematic review (Papastavrou et al., 2011) covering patient views and preferences.

3.3.1.2 2021 surveillance summary

3.3.1.2.1 Personalised care approach to services

Three studies were identified which assessed personalised care approaches (or related approaches that respond to individual needs). A Cochrane systematic review (Coulter et al., 2015) (19 studies, n=10,856 patients) assessed the effects of personalised care planning for adults with long-term health conditions compared with usual care. The broad definition used for personalised care planning was ‘interventions which aim to ensure that individuals' values and concerns shape the way long-term conditions are managed'. The studies looked at a range of interventions designed to involve patients and support self-management. All studies included components that were intended to support behaviour change among patients, involving either face-to-face or telephone support. The key results were as follows:

- Physical health: a significant effect of personalised care was found for glycated haemoglobin (HbA1c) (9 studies; SMD -0.24%; 95% CI -0.35 to -0.14) and systolic blood pressure (6 studies; MD -2.64 mm/Hg; 95% CI -4.47 to -0.82). No significant effect of personalised care was found for diastolic blood pressure (4 studies; MD -0.71 mm/Hg; 95% CI -2.26 to 0.84), cholesterol (LDL-C) (5 studies; SMD 0.01; 95% CI -0.09 to 0.11) or body mass index (4 studies; MD -0.11; 95% CI -0.35 to 0.13).
- Psychological health: a significant effect of personalised care was found for depression (5 studies; SMD -0.36; 95% CI -0.52 to -0.20).

The results of the Cochrane review indicated that personalised care planning leads to improvements in certain indicators of physical and psychological health status, and people's capability to self-manage their condition when compared with usual care.

A further Cochrane systematic review (Mackintosh et al., 2020) considered evidence from RCTs and cluster-RCTs on the effects of interventions designed to increase patient and family involvement in escalation of care for acute life-threatening illness (9 studies, n=436,684). Interactional patient-facing interventions and multi-component programmes compared with usual care indicated there was moderate improvement in patients' knowledge of acute life-threatening conditions, danger signs, appropriate care-seeking responses, and preparedness capacity at 12 months (2 studies; MD 4.20; 95% CI 2.44 to 5.97). Two further studies could not be included in the pooled results on knowledge and they found mixed results. There was mixed evidence on the effects of interventions on self-efficacy and no evidence of effect of multi-component interventions on mortality rates.

A systematic review (Chenoweth et al., 2019) of organisational-level person-centred care for people living with dementia (defined as acknowledging the personality and preferences of the individual) aimed to determine the effectiveness of interventions based on controlled and quasi-experimental studies. Twelve studies (n=2599 patients) comparing person-centred versus usual (non-person-centred) care identified. Results reported within 12 months identified a significant effect for quality-of-life (6 studies; SMD 0.16; 95% CI, 0.03 to 0.28); non-significant effects for neuropsychiatric symptoms (4 studies; SMD 0.06; 95% CI -0.08 to 0.19), well-being (4 studies; SMD 0.15, 95% CI -0.15 to 0.45), agitation (5 studies; SMD -0.05; 95% CI -0.17 to -0.07) and depression (5 studies; SMD -0.06; 95% CI -0.27 to 0.15).

A systematic review and meta-analysis (Goldfarb et al., 2017) considered the effects of patient- and family-centred care interventions in intensive care units. Overall findings from 46 studies (11 randomised, 35 observational studies) identified that 36 studies reported one or more positive outcome measures, whereas 10 reported no significant changes in outcome measures. Based on pooled findings from higher quality (randomised) studies there was a was a significant decrease in ICU length of stay (3 studies; -1.21 days; 95% CI, -2.25 to -0.16) but no significant difference in mortality (5 studies; OR 1.07; 95% CI, 0.95-1.21) when compared with usual care. The authors also note a wide range of patient- and family-centred care interventions were associated with improvements in many patient- and family-important outcomes, but heterogeneity of data prevented pooling of results.

3.3.1.2.2 Feedback and complaints

A NIHR themed review of 9 patient feedback studies examined how patient experience feedback is collected and used. The main aim was to bring together emergent themes and to provide practitioners, policy makers and the public with an overview of the findings of current NIHR funded research and to influence debate, policy and practice on the use of patient experience data. The included studies show what organisations are doing currently and what could be improved. Relevant settings included hospital wards and general practice. Some included studies also explored new ways of mining and analysing 'big' data, using online feedback and approaches to involve patients in making sense of feedback and driving improvements. The main results showed:

- Data is most often used for performance assessment and benchmarking in line with regulatory body requirements, making comparisons with other healthcare providers or to assess progress over time.
- Staff are sometimes unaware of the feedback, or when they are, they struggle to make sense of it in a way that can lead to improvements. They are not always aware of unsolicited feedback, such as that received online and when they are, they are often uncertain how to respond.
- In many organisations, feedback about patient experience is managed in different departments from those that lead quality improvement. Whilst most organisations have a standardised method for quality improvement, there is less clarity and consistency in relation to using patient experience data.
- Staff act on informal feedback in ways that are not always recognised as improvement. Where change does happen, it tends to be on transactional tasks rather than relationships and the way patients feel.
- Organisations should embrace all forms of feedback (including complaints and unsolicited feedback) as an opportunity to review and improve care.
- Organisations should collect, collate and analyse feedback in ways that remain recognisable to the people who provide it whilst offering staff actionable findings.
- Patient experience data should be presented alongside safety and clinical effectiveness data and the associations between them made explicit.

An NIHR commentary of a qualitative study aimed to find out what proportion of patients had concerns about their care, to categorise and understand their concerns, and to assess whether these concerns were in line with the types of patient safety incidents identified by clinicians. The commentary concluded that inpatient surveys can potentially identify patient safety issues and that collecting this data could help trusts identify areas where patient experience could be improved. However, for the data to be useful, it needs to be routinely collected, reviewed and acted upon, which may be difficult to implement. A key challenge in implementing these findings is to ensure that the soft intelligence gathered in patient feedback is integrated with and considered alongside information generated by conventional patient safety reporting systems.

3.3.1.3 Intelligence gathering

3.3.1.3.1 Patient views and preferences

Topic expert feedback suggested that the recommendations for patient views and preferences should:

- incorporate mental capacity, including transient lapses
- advise on consistent use of the patient's preferred name
- include documentation and availability of the documentation for healthcare professionals describing and stating views and preferences, to avoid repetition and increase trust and continuity
- highlight the importance of prioritising the development of care records within acute and primary services.

No evidence was submitted in support of these proposed changes. In addition, these points are addressed directly or indirectly by existing recommendations: mental capacity is referenced in section 1.2 and consideration of mental capacity is entailed in the recommendations which require a tailoring care to the patient's needs and circumstances, taking into account coexisting conditions; use of existing name is mentioned in section 1.5; avoiding repetition is addressed in section 1.4 through continuity of care, including co-ordination; the use of care records is standard in NHS services and not directly relevant to patient experience.

3.3.1.3.2 Involvement of family members and carers

Experts noted the need to recognise and explain the legal implications of power of attorney for health and welfare. This area is covered in detail by NICE's guideline on decision-making and mental capacity.

3.3.1.3.3 Feedback and complaints

Topic experts suggested that all patients should be offered the NHS online feedback to improve patient experience. It was also suggested that the guideline should advise on governance for conducting surveys and questionnaires, meeting and mediating with families who complain, and highlighting the importance of patient advice and liaison services.

3.3.1.4 Impact statement

3.3.1.4.1 Personalised care approach to services

New evidence on personalised care approaches suggests that the effects are not large, they appear greater when the intervention is more comprehensive, more intensive, and better integrated into routine care. There is likely to be a high degree of variation in the style and intensity of personalised care approaches across the range of NHS services, but overall the evidence lends support to the generic recommendations that cover individualised approaches that are tailored to the patient's needs.

3.3.1.4.2 Patient views and preferences

The evidence identified through previous surveillance reinforced the importance of gathering patient views to achieve positive outcomes and that training of healthcare providers may help ensure effective tailoring of services for patients. The new surveillance evidence also highlights the importance of holding discussions with patients so their views, preferences and expectations can be expressed, as recommended in the guideline.

3.3.1.4.3 Patient feedback

The new evidence on patient feedback reinforces NICE guideline CG138 recommendation 1.3.12 which states that patients should be encouraged to give feedback on the care that they receive and that clinicians should respond to any feedback given. The guideline does not outline specifically how patient feedback should be addressed. The guideline committee did not review evidence on methods of feedback but were aware that different methods can elicit different aspects of feedback and therefore multiple formats should be available and used.

The government has outlined a vision for the future of digital healthcare in its policy paper The future of healthcare: our vision for digital, data, and technology in health and care (2018), which notes the need for improved online services and other technology infrastructure in the NHS and to build an open culture where feedback is welcomed. Other national feedback tools include the NHS England friends and family test, which is a mandatory test to ask people if they would recommend the services they have used and offers supplementary follow-up questions. The guideline recommendations which cover feedback and complaints are in line with these recent developments and are complemented by these initiatives.

Overall, the evidence is consistent with CG138 recommendations which cover different forms of patient feedback. Tools such as the friends and family test are already in routine use in the NHS.

3.4 Continuity of care and relationships

3.4.1 Surveillance proposal

The recommendations in this section of the guideline should not be updated.

3.4.1.1 Previous surveillance summary

In previous surveillance of this guideline evidence included a review (Parker et al., 2011) covering definitions of and influences on continuity of care and a study (Wilson et al., 2012) which evaluated patient perceptions about the role of nurses involved in chronic disease management at 7 sites in England and Wales.

3.4.1.2 2021 surveillance summary

3.4.1.2.1 Continuity of care - integrated care

An NIHR commentary of a systematic review was identified. The review aimed to examine international literature on the mechanisms whereby new models of integrated service delivery have an impact on healthcare outcomes. The main outcomes related to the delivery of services, including the views and perceptions of patients, service users and staff. The commentary concluded that it is promising to find strong evidence that integrated care models can improve patient satisfaction and perceived quality of care. However, on the whole, the complexity of interventions make it difficult to conclude the effects on individual people's health, and healthcare systems and resources. Further research may be needed on the challenges of implementing and evaluating new care models to signal an impact on the guideline.

An updated Cochrane systematic review (Laurant et al., 2018) (18 studies) aimed to investigate the impact of nurses working as substitutes for primary care doctors on patient outcomes, processes of care and utilisation, including volume and cost. The nursing level was often unclear or varied between and even within studies. The studies consider nurses involved in first contact care (including urgent care), ongoing care for physical complaints, and follow-up of patients with a particular chronic conditions such as diabetes. The results suggest that care delivered by nurses, compared to care delivered by doctors, probably generates similar or better health outcomes for a broad range of patient conditions, based on low- or moderate-certainty evidence. The results further indicate that patient satisfaction is probably slightly higher in nurse-led primary care, based on moderate-certainty evidence and quality-of-life may be slightly higher, based on low quality evidence. The review also found that, compared to doctors, nurses probably have longer consultations, and their patients are slightly more likely to keep follow-up appointments. The effects of nurse-led primary care on the amount of advice and information given to patients, and on whether guidelines are followed, were uncertain.

A review and meta-analysis (Mazzarello et al., 2019) considered an in-hospital shared care approach to postoperative management of adult non-cardiac surgery patients. Evidence from 2 RCTs (n=729 patients) and 2 nRCTs (n=258 patients) did not identify any association between shared care or control groups for mortality (OR 1.76; 95% CI, 0.65 to 4.8) or length of hospital stay (MD −1.41; 95% CI, −3.18 to 0.35).

A review and meta-analysis (Monterosso et al., 2019) of nurse-led models of care (4 to 6 months) for adult cancer patients included 15 tumour specific trials. The meta-analysis found significant benefit for cognitive (MD 4.04; 95% CI, 0.59 to 7.50) and social function (MD 3.06; 0.14 to 5.97) and reduced fatigue (after intervention completion) (MD −4.45; −7.93 to −0.97). Conversely, the analysis did report worse appetite loss for nurse-led models of care (MD 4.43; 0.08 to 8.78).

A review and meta-analysis (Pascucci et al., 2021) considered the impact of interprofessional collaboration across health and social care teams on chronic disease management. Evidence from 23 RCTs showed significant reductions in systolic blood pressure (MD -3.70; 95% CI -7.39 to -0.01), glycosylated haemoglobin (MD -0.20; 95% CI -0.47 to -0.07), LDL cholesterol (MD -5.74; 95% CI -9.34 to -2.14), diastolic blood pressure (MD -1.95; 95% CI -3.18 to -0.72), days of hospitalisation (MD -2.22; 95% CI -4.30 to -0.14).

A review and meta-analysis (Valentijn et al., 2018) assessed person-centred integrated care for chronic kidney disease (defined as continuum of care and integrated strategies). The findings at 12 months from 14 RCTs (n=4693) found no effect on all-cause mortality RR, 0.86; 95% CI, 0.68 to 1.08) or health-related quality-of-life (SMD, 0.02; 95% CI, -0.05 to 0.10). There were uncertain effects on renal replacement therapy (RR, 1.00; 95% CI, 0.65 to 1.55), serum creatinine levels (MD, 0.59 mg/dl; 95% CI, -0.38 to 0.36), and estimated glomerular filtration rate (kidney function) (MD, 1.51 ml/min per 1.73 m^2; 95% CI, -3.25 to 6.27). There was however some benefit on all-cause hospitalisation (RR, 0.38; 95% CI, 0.15 to 0.95) and BP control (RR, 1.20; 95% CI, 1.00 to 1.44).

3.4.1.2.2 Continuity of care – patient navigation

A review and meta-analysis (Ali-Faisal et al., 2017) studied the effectiveness of patient navigation models on healthcare utilisation outcomes (the patient groups were not identified in the abstract). Results from 25 RCTs, of which 12 included trained lay navigators and 9 health professionals, identified that patient navigation models significantly improved outcomes for ‘access to health screening’ (OR 2.48; 95% CI, 1.93 to 3.18) and ‘attend a recommended care event’ (OR 2.55; 95% CI, 1.27 to 5.10) compared to usual care.

A review and meta-analysis (Wells et al., 2018) considered the impact of patient navigation models on satisfaction with cancer care. Pooled evidence from 5 studies (1 RCT and 4 non-RCTs) was assessed. Evidence from the RCT showed a significant increase (standardised mean difference (SMD) 2.30; 95% CI 1.79 to 2.80), whereas non-RCTs showed no significant association between patient navigation and satisfaction with cancer-related care (SMD 0.39; 95% CI 0.02 to 0.80).

3.4.1.3 Intelligence gathering

3.4.1.3.1 Continuity of care and relationships

Topic expert feedback suggested the need for shared care records across health providers to improve continuity of care. No evidence was submitted relating to this area, which is technically covered in recommendation 1.4.3 which covers clear and timely exchange of patient information between health and social care professionals; there is also a link to the Health and Social Care Safety and Quality Act 2015 which provides information about the duty to share information. It was also suggested that this section should advise local explanation of the multidisciplinary team pathway in order that patients understand any apparent inconsistency between different practitioners. However, such explanations are likely to come under the remit of local services.

3.4.1.4 Impact statement

The evidence identified through the previous surveillance was considered to be consistent with current recommendations on continuity of care and relationships.

Evidence from the current surveillance review was generally lacking in quality and quantity to provide any clear indication of effectiveness of the different models of care for individual patient groups and settings. It should also be acknowledged that models of continuity of care is difficult to research given the often complex and multifaceted nature of interventions and interactions with existing care models and varied transits through the care system. However, there was general improvement in patient outcomes where models of care were focused on providing continuity and consistency of care, although the effects are seldom large. Overall, the new evidence provides some support for the existing recommendations.

3.5 Enabling patients to actively participate in their care

3.5.1 Surveillance proposal

The recommendations in this section of the guideline should not be updated.

Please note: the current review covered the following sections:

- Communication, recommendations 1.5.1 to 1.5.10
- Information, recommendations 1.5.11 to 1.5.19
- Education programmes, recommendations 1.5.28 to 1.5.29

The section on shared decision making, recommendations 1.5.20 to 1.5.27, were not included within the current surveillance review as they have been replaced by NICE's guideline on shared decision making.

3.5.1.1 Previous surveillance summary

Previous surveillance included a systematic review (Hudon et al., 2012) of patient-centred care in adult chronic disease management, a systematic review and meta-analysis (Henry et al., 2012) of non-verbal communication and a study (Kazimierczak et al., 2013) of providing information for patients with cancer.

3.5.1.2 2021 surveillance summary

3.5.1.2.1 Information – self-management support

A systematic review and meta-analysis (Zimbudzi et al., 2018) assessed RCT evidence on the effectiveness of self-management support interventions in patients with comorbid diabetes and chronic kidney disease (8 studies, n=835 patients). Compared with usual care the interventions there was significant improvement in self-management activity (SMD 0.56; 95% CI 0.15 to 0.97) and significantly reduced systolic blood pressure (MD −4.26 mmHg; 95% CI −7.81 to −0.70) and glycated haemoglobin (MD −0.5%; 95% CI −0.8 to −0.1). The study was not able to establish which components were more effective, but provider reminders, patient education, and goal setting were associated with improved outcomes.

A systematic review and analysis (Boogaard et al., 2016) of RCTs assessed the efficacy of self-management programs in patients experiencing side-effects of breast cancer treatment (9 studies). Self-management interventions were found to significantly improve health-related quality-of-life (SMD 0.49; 95% CI 0.16 to 0.82), coping ability (SMD 0.19; 95%CI 0.03 to 0.34) and fatigue (SMD -0.94; 95% CI -1.69 to -0.18).

A systematic meta-review (Pinnock et al., 2017) of RCTs investigated whether supported asthma self-management reduces use of healthcare resources and improves asthma control. The analysis identified that supported self-management can reduce hospitalisations, accident and emergency attendances and unscheduled consultations and improve markers of control and quality-of-life for people with asthma (270 RCTs; no data provided in the abstract). Based on an analysis from 24 RCTs providing self-management support does not significantly increase total healthcare costs (SMD 0.13; 95% CI -0.09 to 0.34).

A systematic review and meta-analysis (van Eikenhorst et al., 2017) assessed pharmacist-led self-management interventions to improve diabetes outcomes (24 RCTs, n=3610 patients). The interventions included education on diabetes complications, medication, lifestyle and teaching of self-management skills. The interventions led to significant improvement in HbA1c levels (mean 0.71% (95% CI -0.91, -0.51; overall effect $P < 0.0001$) and had a positive effect on blood pressure (SBP -5.20 mm Hg; DBP -3.51 mmHg) and BMI (-0.49 kg/m^2).

3.5.1.2.2 Education

An updated Cochrane systematic review (Anderson et al., 2017) (22 studies, n=76,864) aimed to investigate the impact of the educational component of cardiac rehabilitation, compared with usual care, on mortality, morbidity, health-related quality-of-life (HRQoL) and healthcare costs in patients with coronary heart disease. The results indicated that there is insufficient information at present to fully understand the benefits or harms of patient education for people with heart disease, but the evidence broadly supports current guidelines that people with heart disease should receive comprehensive rehabilitation that includes education.

An updated Cochrane systematic review (Köpke et al., 2018) (1 new and 10 existing studies, n=1387) aimed to evaluate the effectiveness of information provision interventions for people with multiple sclerosis (MS) that aim to promote informed choice and improve patient-relevant outcomes. Comparators were usual care or other types of information provision. The active intervention components included decision aids, decision coaching, educational programmes, self-care programmes, and personal interviews with physicians. All studies used one or more components, but the authors noted heterogeneity between studies. The results indicated that information provision for people with MS increases disease-related knowledge, with less clear results on decision making and quality-of-life.

A meta-analysis (Kao et al., 2016) of RCTs assessed the effect of psycho-educational interventions on quality-of-life in patients with implantable cardioverter defibrillators (7 studies, n=1017). In comparison with the control groups there was a significant improvement in physical component summary scores (MD 2.08; 95% CI 0.86 to 3.29) but no significant benefit recorded for the mental component summary scores of patient quality-of-life (MD 0.84; 95 % CI -1.68 to 3.35).

3.5.1.3 Intelligence gathering

3.5.1.3.1 Enabling patients to actively participate in their care

Topic expert feedback highlighted the need to ask open questions and to check understanding, which is covered by recommendations 1.5.7 and 1.5.8.

Topic experts further suggested the use of multimedia to supplement written materials, but no evidence was submitted in support of this.

3.5.1.3.2 Technology

Topic experts suggested the recommendations would be made more relevant with acknowledgement of a role for technologies in providing information, communication and gathering views, including mobile phone applications, videos and text messaging and online patient portals. However, no evidence was submitted in support of related proposals.

3.5.1.4 Impact statement

3.5.1.4.1 Patient-centred care in chronic disease management

Overall, the evidence identified previous surveillance was considered to be consistent with current guidance.

3.5.1.4.2 Technology

In response to comments that the guideline could clarify the role of technologies in providing information, communication and gathering views, the guideline does already allow for this interpretation as the recommendations are not prescriptive about the mode of communication. For example, recommendation 1.3.1 advises adopting an individualised approach to healthcare services that is tailored the patient's needs and circumstances, taking into account their ability to access services, personal preferences and coexisting conditions. This allows for differing forms of communication, including the use of new and emerging technologies. In addition, recommendation 1.5.13 mentions the patient should be given information in an accessible format, which could be in a digital format of written text, pictures or symbols.

In addition, the government has outlined a vision for the future of digital healthcare in its policy paper The future of healthcare: our vision for digital, data, and technology in health and care (2018), which notes the need for improved online services including digital tools, advice and apps. A vision for digitally enabled care across the NHS is also outlined in the NHS Long Term Plan (2019).

Given the generic nature of the recommendations in CG138, the guideline is broadly consistent with intelligence supporting the use of new technology for providing information and communications. More detailed and context derived evidence-based recommendations concerning the adoption of new or emerging technologies (for example, for communication and consultation) are outlined in NICE guidelines for specific conditions.

3.5.1.4.3 Information – self-management support

New evidence on self-management support broadly supports the approach outlined in the recommendations to enable and provide information about self-care and self-management. There is likely to be a need to adapt approaches to specific patient groups, but overall the evidence lends support to the generic recommendations that cover self-management.

3.5.1.4.4 Education

New evidence on education interventions for patients was limited and too diverse to draw any general conclusions about education programmes, but the recommendations are unlikely to be affected either way as recommendation 1.5.28 is general in nature and advocates evidence-based approaches.

3.6 Areas not currently covered in the guideline

In surveillance, intelligence was identified for areas not covered by CG138. This new intelligence has been considered for possible addition as new sections of the guideline.

3.6.1 Intelligence gathering

Topic experts suggested the following areas not currently covered by the guideline:

- Specific guidance for specialist pharmaceutical services. It was suggested that NICE review the extent to which the current guidance addresses this specific area. However, this area is covered by NICE's guidelines on Medicines adherence and medicines optimisation.

Additionally, there is also the NICE endorsed resource 'Pharmaceutical care plan' in the tools and resources section of NICE guideline CG138. Therefore as this area is addressed in other NICE products, it will not be added to CG138.

- Specific guidance on older people, including frailty, as the population of England is ageing and the mean life expectancy has increased since the guideline was published. The proportion of the elderly age group with common conditions has increased. It was also stated more people living with dementia indicates the need for guidance for this sub-group. Whilst the population is ageing it has not changed significantly since publication in 2012. When developing the guideline, it was recognised that older people would be key beneficiaries of the NICE guideline CG138, and they may have multiple-morbidities or be socially vulnerable. The guideline covers patient experience for all people who receive healthcare for all adult age groups. In addition, numerous NICE guidelines on older people and specifically on areas such as multimorbidity and dementia address in detail the needs of an older and an ageing population and cover many of the themes outlined in CG138 for these populations. Therefore, as this area is addressed in other NICE products it will not be added to CG138.
- Advice on patient experience for under-served groups to address inequalities in this area. The guideline already recommends that healthcare professionals should take into account the requirements of the Equality Act 2010 and make sure services are equally accessible to, and supportive of, all people using adult NHS services (recommendation 1.1.6). Additionally, an equality impact assessment was carried out during the development of the guideline. This document confirmed that the recommendations have been developed to promote equalities for all people who receive healthcare within the adult NHS services, irrespective of age, gender, ethnicity, disability, religion or beliefs, sexual orientation and gender identity or socio-economic status. Therefore, as this area is addressed in other NICE products it will not be added to CG138.

3.7 Research recommendations

The guideline CG138 makes no recommendations for research.

3.8 References

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