Multimorbidity:
Stakeholder workshop minutes

- Stopping treatment or 'de-prescribing' – highlighted as a difficult conversation to have with patients which can be very upsetting for patients. Noted that 'shared-decision making' between patient and prescriber is very important here.
- Mark Baker provided some context to the guideline: there was a line in the quality standards which referred to complex needs in long-term morbidity and multimorbidity. He noted these are the people who are older, with large number of conditions and polypharmacy. The tail end of the distribution (slides from Bruce Guthrie presented by Norma). He highlighted that this guideline would differ from adherence guideline as the adherence guideline did not address this particular population
- **Management of care** is important but it is more about addressing the underlying issues as opposed to case management per se. Empowering physicians to make decisions is key. Discussed if this guideline was about integrated care (to reduce multiple appointments) vs. medication (multiple treatments). Mark Baker noted that this guideline is not about organisation of care – mental health (RCPsych) is covering this in a guideline. Group acknowledged the two are interrelated.
- **Population**:
  - o Either focus on common co-morbidities and describe the complexity of treating these or take social deprivation as an angle.
  - o Could number of drugs or number of avoidable admissions (i.e. problems associated with multimorbidity) be used to define the population? Identifying the problems with multimorbidities and working backwards was suggested as a sensible approach.
  - o If number of drugs taken as definition of population, we could miss out on some important groups.
  - o Discussed the tension between focussing on defining conditions vs. defining the problems (e.g. poor QoL, avoidable admissions, polypharmacy etc.)
  - o Group was happy with suggested **exclusions**: children (should be another guideline); no physical morbidity (mental health only multimorbidities to be covered by RCPsych). Group highlighted that the impact of long term physical conditions on mental health is important.
  - o Group noted that from Bruce Guthrie's research of common multimorbidities, depression and pain came up consistently in the top 5 conditions.
- Group discussed that assessing the baseline risk of the person in front of you is usually done by taking into account their age and that being more specific than that is hard. They highlighted that there is great variability in how clinicians deal with uncertainty and that trying to reduce this uncertainty in these grey areas would be helpful.
- The 'sparrow indicator' in Scotland was mentioned as a way of identifying those who will have multiple admissions in an upcoming year, it was noted this indicated it is primarily driven by age.
- Group acknowledged that NICE guidelines are contributing to some of the problems.

- **Service setting**: group agreed needs to be all settings and noted that often polypharmacy starts at a specialist level and then passed onto primary care.
- **Quality of life** (QoL) and QALYs may need to be approached differently – will need to incorporate both health and social dimensions. There is likely to be a lack of literature on QoL in people with multimorbidities. In those taking a high number of drugs (e.g. >4) they are likely to get all the adverse events, and possibly less of the benefits, resulting in a decrease in QoL. Group felt it was important to focus on the fact that stopping treatment is about enhancing QoL and not just simply because people are reaching the end of life.
- **Original work:** Suggested we conduct an original piece of work where we look at existing condition specific guidance and attempt to collate this to provide a ranking of treatments based on time to achieve benefit. Mark Baker said he was happy for us to take the risk of trying this type of work and acknowledged it may not be feasible/ we may not succeed. Noted that (HE) modelling may be difficult as RCT evidence for multimorbidities is likely to be weak, uncertainty is likely to be significant but sensitivity analyses could be done. Possibility of using real-world data/cohorts discussed.
- **Outcomes:** place of death? group felt this was more appropriate for care of the dying adult guideline
- **Conclusion:** Group agreed that the guideline should address principles of managing multimorbidities is important and would be useful and that some sort of ranking of treatments for common morbidities would be useful (if feasible). Regarding population it was felt being too specific may lead to groups being excluded. Suggested that a question around identifying the relevant population was needed

GDG constituency

Possibly additions and general comments:

- ortho-geriatricians – 'extreme' practitioners of multimorbidities
- clinical pharmacologist – often have a polypharmacy interest
- Different types of pharmacists – e.g. admissions pharmacists will have a good overview of different conditions
- Advanced practitioners (nurses) – will have a good overview of different conditions
- Surgeons – often over treat
- Emergency care physicians / acute care physicians?
- Someone with expertise in shared decision making and obtaining consent? (for stopping treatment)
- Palliative care – focus on ong-term care not just end of life
- Liaison psych would be good
- Practice nurse – noted that they are very hard to recruit
- Intermediate care?
- Oncologist – co-optee? Often over treat.
- Demographer – could have an actuary instead? Mentioned that companies may offer their services for free as part of their corporate social responsibility

- Academic in multimorbidities as co-optee– Mark Baker was reluctant as this may lead to academic debate.
- Methodologist – Norma highlighted that the technical team fulfil this role.

- Given the dynamic and fluid nature of MM, the group felt that the guideline should provide general principles of care. This would provide a consistent approach. Given the unique nature of MM, specific principles may only benefit certain individuals and act as a barrier to others. What works for one individual, may work against another. General principles were sufficient and enabled patients to challenge physicians on the care they were/were not receiving.

Population:
- The group considered looking at the MM population from two different perspectives: 1) from a complexity perspective, how complex is it to manage MM? 2). from a life-limiting expectancy perspective, shouldn't we target where the impact is greater? Complexity of treatment issue vs. impact of effect issue.
- Mental health: the group noted that people with MM often have accompanying mental health issues. Mental health issues, such as depression and anxiety, lead to worse outcomes for people with MM.
- Age range: one member of the group felt that discussion document as it stands focuses on the elderly and did not relate to her. Similarly, a mother of a young boy with autism was concerned that the scope did not consider children. The group noted that it is important to take a preventative approach to MM, addressing issues at an early age may prevent the development of multiple chronic conditions. However, it was acknowledged that it would be difficult to consider the whole life-cycle in this guideline.
- Group members felt that it was not appropriate to list conditions that will be considered under the MM guideline – a general definition was required.
- The group noted that there was no mention of concordant/discordant MM in the discussion document.
- The group highlighted that there are many people with a number of chronic conditions that do not consider themselves to have a MM. Individuality is key. There are commonly occurring patterns of MM, and individuals go between a number of physicians. It was suggested that individuals who attend the GP frequently should receive specialist input and co-ordination of care (action - add individuals who frequently attend the GP to 'groups that require a tailored approach').
- Members of the group raised concern that there is the issue of masked or hidden conditions, which are difficult to detect and individuals may not therefore be recognised as having multiple morbidities. Concern was also raised in relation to those individuals with communication issues (i.e. individual with intellectual disabilities, autism, etc.).
- It was felt that 'people with falls' would not add value and was irrelevant, as other guidance is addressing this issue.

Management:
- Technology: the application of technology was noted as being missing from the discussion document, and an important aspect of management. The group noted that there is a need for a joined up approach and centralised system to aid data sharing. One member of the

group noted that she had been to the same hospital four days in a row for assessment of her diabetes care (eye clinic, HBAIC measurement, nutritionist, and chiropodist); neither clinic had access to the results of her other tests and were unaware of her other treatments.

- Discordant care: it was noted that the discussion document considered the care of individuals with MM from a top down perspective. It could be more relevant to view MM from the perspective of three patients with commonly occurring patterns of MM, and follow their journey. The care that many experience is decentralised and there is little joined up thinking. Greater communication between generalists and specialists was essential. Clear objectives need to be set, agreed, and communicated between all physicians involved in an individuals care. It was felt that case management, rather than consolidating, has disseminated the problem.
- It was suggested that transition in health status could provide a predicable maker for change and should prompt a MM approach (e.g. getting ready for surgery or a change in mental health status (bereavement)). There is a need to identify points in a patient's pathway that warrant reassessment.
- Members of the group felt that it is very difficult for GPs to navigate through the decision making process. Guidance on how to apply guidance and interpret the evidence would be helpful. Furthermore, it was noted that GPs often want to consider reduction of risk of future disease but that it is difficult to find this information out.
- It was suggested that those individuals with more than three conditions should have a care coordinator, particularly those individuals with discordant conditions.
- It was noted that guideline recommendations are often about 'adding', but it is also important to empower physicians to remove elements of care ('stop, think, remove'). Furthermore, it was noted that stopping treatment was a difficult conversation to have with patients.
- Non-medical interventions were not evident in the discussion document. Members stressed the importance of life-style in the management of MM (i.e. socio-economic status, social isolation, social networks/social support, physical exercise, complimentary therapy).

GDG constituency
- Statistician – this guideline is out of the normal framework and requires expert statistical support and independent validation.
- Doctor heavy – more nurses required, either community or practice
- Allied health professional – such as an occupational therapist
- Input from social care / public health
- General physician with expertise in concordant clinics
- Philosopher – lateral thinking required
- Co-optees: experience of complementary medicine / nutritionist

Population

- Should be as broad as possible, defining by number of conditions is not 'real world'.
- The output of the guideline should be relevant to everyone.
- Agreed that children and those with multiple mental health difficulties should be excluded as these groups merit their own guideline.
- Integration of health and social care.

Patient perspective

- How do we incorporate patient's requests for information and risk? Currently this is passive. Patients often leave their clinicians and make an uninformed decision; they don't always follow medical management.
- What level of engagement do patients want in their medical decisions?

- Elderly patients and vulnerable people with multimorbidities plus children in transition are currently being failed. Consultation is driven by the condition not by the person.
- Not age related, it is about the number and nature of the patients conditions.
- Important to shift the system to an approach that takes evidence and contextualises it to the patient.
- The emphasis should be supporting informed consent and better shared decision making with patients.
- Important to recognise that a patient with a long term condition is an expert (or a carer who is caring for a patient with a long term condition).
- Requirement to reframe mind-sets, attitudes and beliefs.

Mental Health perspective

- Addressing the resilience of people with mental health problems is very important.
- Patient with multiple mental health issues but no physical problems do not exist (currently excluded population in scope).

Evidence base

- Most of the evidence is not based on people with multimorbidity, but there is some identified evidence within mental health.
- Awareness that normal evidence base will not work for this guideline.
- Potential to cross reference different kinds of data sets? Not something normally done but could be relevant for this guideline

Output of this guideline

- Currently finding the absolute gain for patients is very time consuming for clinicians – need to make sure the evidence is accessible and user friendly for frontline clinicians.
- Huge risk of polypharmacy, particularly for GPs, since there are currently lots of single condition guidelines – should we be making better use of the evidence we already have?
- NICE recs are currently not individualised – they apply to everyone. Do we need a fundamental shift in NICE output?
- Need to differentiate between risks and conditions.
- Guidelines currently defined as diagnosis, could be defined by more broad interventions (e.g.CBT)

Non pharma and pharma interventions

- Often good evidence for both NP and P as separate interventions. It was suggested that these would be more effective if both had equal emphasis. Can NICE be more flexible about the strength of evidence?

Promotion of guidance with smarter IT solutions

- A NICE NED indicated that NICE are currently developing work focussing on producing a unit of guideline output that is somewhere between one single recommendation and a 500 plus PDF document.
- Need evidence from single conditions put together creatively using an IT approach.
- Present the evidence in a way that will help a clinician find a specific piece of information for people with certain conditions.
- As some of the single condition guidelines are relatively old, the presentation of the evidence for different guidelines is very different. Could update existing guidance and generate a common currency in order to compare guidelines?
- Can use IT to make the guideline an agile tool that can be used as an interactive resource in front of patients (a useable, user friendly resource rather than a pdf document to read).
- Need a practical, patient focussed system.

Education

- Should the scope include undergraduate and postgraduate education (e.g. benefits of a junior doctor treating 20 patients with multimorbidity over 1 year versus 1 term of 1 specialty)?
- Current guideline in development on staffing levels.

Health and social care

- How can the scope integrate health and social care?
- How can the scope capture socio-economic dimensions appropriately?
- What can one do about the socio-economic risks of multimorbidity?

GDG constituency

- 2 x clinical pharmacists
- Palliative care – questioned usefulness of this member
- Public health representation
- Behavioural psychologist
- Expert in demography
- Health Education England rep
- IT rep?
- Involvement of NICE Implementation earlier in development process.