Shared Decision Making and Consent: Phase 1 Final Report

Appendix C

Original Use Case Scenarios

June 2021

Contents

1 Vascular Surgery

Scenario Background

Abdominal Aortic Aneurysms (AAA) are a common condition affecting mainly older men. It is a condition which has different treatment options, and the patients almost always have co-morbidities.

An AAA occurs when there is weakening of the arterial wall and as a result the artery enlarges and eventually can burst. The risk of rupture increases exponentially with size. Rupture is usually fatal and accounts for about 5,000 deaths per year in the UK.

Treating an AAA before it has burst carries risk and therefore a risk benefit analysis has to be performed with the patient to decide on which treatment modality is appropriate. Not all treatment modalities are suitable for every patient.

The different treatment modalities are:

1. Conservative (will never have a procedure).
2. Deferred (may have a procedure in the future).
3. Open surgery.
4. Endovascular (minimally invasive).

Patient Scenario

John is a 70-year-old man has been found to have an incidental AAA as part of another routine scan. John has no symptoms from his aneurysm.

He has is worried as stories about AAAs as his father died of a ruptured aneurysm.

He is referred to see the consultant vascular surgeon.

The outline of sequence of events with decisions made are shown below:

1. Initial Appointment:
    a. Initial clinical assessment.
    b. Information given to the patient. The nature of aneurysmal disease. Why it is important, potential treatment options but with context. (ie relative risks of dying with or without treatment).
    c. It is possible that after this initial consultation that the patient will never be suitable for intervention and after discussion with the patient he is discharged.
    d. Initial management:
        i. Smoking cessation.
        ii. Medications e.g., Aspirin and cholesterol lowering.
        iii. General health advice- keep exercising.
        iv. Driving – if the AAA is larger than 6cm, the patient must inform DVLA and stop driving. This can be a factor for the patient to increase their desire to have intervention.
    e. Investigations and assessments arranged:
        i. CT imaging.
        ii. CPX testing.
        iii. Anaesthetic review discussion of anaesthetic options including risks.
2. Patient returns for investigations and assessments.

3. *Patient is discussed at MDT as to best treatment option clinically. Note this is a clinical decision.*
4. Review appointment:
    a. Treatment options review in light of the results of the investigations and anaesthetic opinion.
    b. Decision made as to treatment option, or discharge.
5. Treatment if indicated.
6. Admission for treatment.
7. Review post treatment, is discharged or follow up programme as needed.

Patient Background

Patient is “John” a 70 year old man.

John is quite active and enjoys a reasonable amount of walking and gardening

He drives and regularly takes his wife out to nice places to walk with lunch or afternoon snack.

He has several grandchildren through his 2 children he and his wife visit them quite frequently to see them all and do some child minding.

He had a routine scan for ?? and this showed the enlarged artery. He doesn’t smoke, but enjoys a beer or glass of wine in the evenings (approx. 6 units a week).

No preparational research is needed by the patient.

2 Polypharmacy

Background

Polypharmacy - the use of multiple medications – is common in older patients with multimorbidity and is associated with poor outcomes.[1] Several factors including adverse drug-drug and drug-disease interactions are responsible and may contribute to and be compounded by decreased renal and hepatic clearance of drugs in older people.[2] Criteria for polypharmacy are mixed but it generally occurs where a significant number of prescribed medications are taken over an extended period of time, although not all polypharmacy is clinically inappropriate.[3] Interventions are commonly targeted at those on 10 or more medications. Recognition of polypharmacy related harms have informed the drive for deprescribing:

"Deprescribing is a collaborative process, with the patient and/or their carer, to ensure the safe and effective withdrawal of medicines that are no longer appropriate, beneficial or wanted, guided by a person-centred approach and shared decision-making."

English Deprescribing Network[4]

For some medications and in certain circumstances, temporary deprescribing (as a 'drug holiday' may be indicated. For example, drug holidays of 1 – 2 years are routinely considered for patients after 3 – 5 years of oral bisphosphonate therapy for osteoporosis, primarily due to the risk of atypical femoral fractures (AFF).[5,6] Gastrointestinal side effects (heartburn, acid reflux, or other) are the most given reason for bisphosphonate non-adherence in osteoporotic women.[7] Rarer complications include AFF, osteonecrosis of the jaw or external auditory canal, and oesophageal reactions.[8]

Vignette

Doris is a 70-year-old woman of Asian origin, who attends her GP for an annual medication review. She lives alone in a one-bedroom high-rise council flat in London. She has multiple cardiovascular risk factors including a 45 pack-year smoking history, hypertension,

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[1] Masnoon, N., Shakib, S., Fortin, M., Kalisch-Ellett, L., Caughey, G. (2017). What is polypharmacy? A systematic review of definitions. BMC Geriatric, 17(1), 230.

[2] *Ibid.*

[3] NICE (2017). Multimorbidity and polypharmacy. Key therapeutic topic.

[4] EDeN (2019). English Deprescribing Network [website]

[5] GPnotebook. Drug holiday from bisphosphonates [website].

[6] Reid, I. (2021). Bisphosphonate holidays. Drug and Therapeutics Bulletin. 59. 35 - 36

[7] Goldshtein, I., Rouach, V., Shamir-Stein, N., Yu, J., Chodick, G. (2016). Role of side effects, physician involvement, and patient perception in non-adherence in oral bisphosphonates. Advanced Therapeutics. 33(8). 1374 – 84.

[8] BNF (2021): Alendronic acid. British National Formulary [online].

hyperlipidaemia, and type 2 diabetes. She is a healthy weight. She has mild heart failure following a myocardial infarction (heart attack) five years ago. She has had an endoscopy which confirmed gastro-oesophageal reflux disease (GORD) in the past but until recently her symptoms of acid-heartburn (dyspepsia) were controlled using omeprazole (a PPI which reduced stomach acid). A bone density (DEXA)[9] scan 6 months ago showed no significant deterioration in her osteoporosis.

Doris takes multiple prescribed medications including:

Medication	**Dose**	**Route**	**Freq.**	**Indication**
Ramipril	2.5mg	PO[10]	OD[11]	Heart Failure
Bisoprolol fumarate	2.5mg	PO	OD	Heart Failure
Clopidogrel	75mg	PO	OD	Secondary prevention
Simvastatin	60mg	PO	OD	Secondary prevention
Amlodipine	5mg	PO	OD	Hypertension
Metformin hydrochloride (modified release)	1g	PO	OD	Type 2 Diabetes
Omeprazole	20mg	PO	OD	GORD
Diclofenac potassium	75mg	PO	PRN	Osteoarthritis
Alendronic acid	10mg	PO	OD	Osteoporosis
Colecalciferol (10µg) with calcium carbonate (1.25g) (Calcichew-D3® Forte)	1 tablet	PO	OD	Osteoporosis

Appointment:

During the appointment the GP uses her clinical judgement as well as the STOPP START Medication Review Tool as a checklist to help identify if she is taking any inappropriate medications. She invites Doris to take part in a collaborative discussion, where they agree the following:

Medication	Action	Reason
Omeprazole	Switch to lansoprazole (30mg PO OD)	MHRA[12] discourages concomitant use of clopidogrel and omeprazole

[9] DXA = dual-energy x-ray absorptiometry – a gold standard measurement of bone mineral density

[10] PO = *'per os'* (by mouth)

[11] OD = Once a day; BD = Twice a day ; TDS = Three times a day ; QDS = Four times a day ; *nocte* = at night.

[12] MHRA = Medicines and Healthcare Products Regulatory Agency

Simvastatin	Switch to atorvastatin (20mg PO nocte)	MHRA recommends maximum dose of 20mg simvastatin with concomitant amlodipine use
Diclofenac	Stop. Doris agrees to trial a low dose topical NSAID for her knee pain.	Diclofenac is contraindicated in cardiovascular disease Regular use can exacerbate GORD and causing GI ulcers

During the appointment Doris discloses that her symptoms of dyspepsia have been getting worse recently. She has no ALARM[13] symptoms and her recent blood results showed normal haemoglobin and platelets. The GP reassures Doris that another endoscopy is not necessary at this stage[14] and notes that long term use of alendronate is a possible cause of the dyspepsia. She tells the patient that as she has been taking the bisphosphonate for over five years a medication 'holiday' should be considered.

The GP invites Doris to make a shared decision and they discuss the following options and their risks and benefits:

- Option 1: 'Do nothing' – Keep taking the alendronate and GP provision of lifestyle advice (including smoking cessation, reducing alcohol intake, healthy eating & exercise strategies). GP explains that there is some evidence that as an Asian woman Doris is at higher risk of AFF (and lower risk of other fractures) and that this risk rises rapidly after five years.[15] Also, if the drug is causing the dyspepsia, her symptoms are likely to continue.
- Option 2: Alendronate holiday – temporarily stop taking the drug (for up to 2 years). The GP explains that in one study, compared to current users, discontinuation of oral bisphosphonate reduces the risk of AFF by 60% after 3 - 15 months and by 87% > 15 months, but that the absolute risk was low.[16] She also explains evidence that, after stopping alendronate, biochemical markers of bone turnover increase to pre-treatment levels over 1 – 2 years and that in one observational study of 11,500 women who stopped bisphosphonates after 5 years, there was no increased risk of fracture over the following three years compared to those continuing treatment.[17]

[13] ALARM symptoms include: Anaemia, dysphagia (difficulty swallowing), haematemesis (vomiting blood), melaena (passage of black tarry stools), persistent vomiting, involuntary weight loss.

[14] GPnotebook. NICE – management of uninvestigated dyspepsia in primary care.

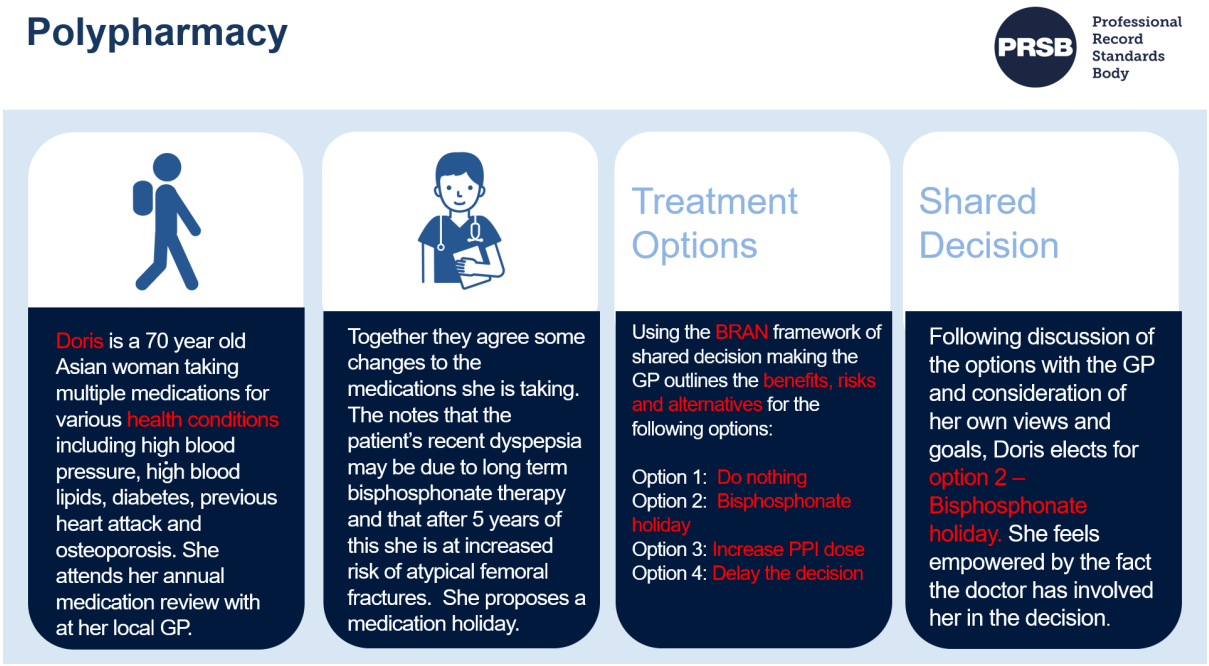
[15] See reference 7.

[16] Black *et al.* (2020). Atypical femur fracture risk versus fragility fracture prevention with bisphosphonates. New England Journal of Medicine. 383. 743 – 753.

- Option 3: No medication holiday and increase the dose of lansoprazole (to 60mg PO OD). The GP explains the risks of polypharmacy and the benefits of deprescribing.
- Option 4: Delay the decision and review.

Doris chooses option 2 and is satisfied with the decision.

Storyboard



3 Gynaecology

Background

Pelvic organ prolapse (POP) is where a woman's pelvic organs are no longer supported by her pelvic floor and can therefore bulge (prolapse) into the vagina.[18] This may involve organs including her uterus (uterine prolapse), bladder (cystocele), rectum or large bowel (rectocele), vaginal vault or small bowel (enterocele).[19] Treatment options include a variety of surgical and non-surgical measures. Until recently, the former included the use of surgical meshes and tapes implanted into the vaginal wall to replace weakened pelvic tissue.

In December 2017, the National Institute for Health and Care Excellent (NICE) recommended that transvaginal mesh repair should only be used in the context of research due to inadequate evidence of efficacy and serious safety concerns.[20] In July 2018 the government announced a high vigilance restriction period that 'paused' indefinitely vaginal mesh and tape procedures to treat urinary stress incontinence in England.[21]

Vignette

Jan is a 60-year-old multiparous (gravida 3, para 2)[22] Caucasian woman who has attended her local GP surgery for a routine cervical screening test. Her two sons were born via normal vaginal delivery without complications. She continues to work part-time as a barrister. She has never had surgery. She rarely drinks alcohol but has smoked 5 - 10 cigarettes a day for 50 years. Her BMI (body mass index) is high at 31.1. During the examination the practice nurse notices a bulge to the entrance of her vagina (introitus) when she is straining and alerts the GP. Jan tells the doctor that she had noticed a sensation of pressure, but it had not bothered her until now. She has regular bowel motions. She discloses that she has very occasionally leaked urine when she coughs, laughs, or sneezes, but denies having to rush to 'spend a penny' and says she does not need to go any more than usual (about five times a day). Her bladder is not palpable, and no masses are found during bimanual examination.

The GP explains to the patient her diagnosis of uterine prolapse and invites her back for an appointment to discuss her options.

Appointment 1:

Jan is prompted by her doctor to 'Ask 3 questions' and the following is discussed and recorded.

What are my options?

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[18] RCOG (2020). Pelvic organ prolapse.

[19] BMJ Best Practice (2020). Uterine prolapse.

[20] NICE (2017). Interventional procedures guidance [IPG599]. Transvaginal mesh repair of anterior or posterior vaginal wall prolapse.

[21] NHS Improvement and NHS England (2018). VAGINAL MESH: HIGH VIGILANCE RESTRICTION PERIOD: Immediate action required, all cases should be postponed if it is clinically safe to do so [letter].

[22] Gravidity = the number of times a woman has been pregnant; Parity = the number of times a woman has given birth to a foetus of 24+ weeks gestational age

- Option 1: ‘Do nothing’ – take no further action.
- Option 2: Delay the decision (observation/watchful waiting)
- Option 3: Conservative management including observation/watchful waiting, provision of lifestyle advice or goal setting (including smoking cessation, diet and exercise with the goal of weight loss) + pelvic floor exercises
- Option 4: Referral for gynaecological review

What are the pros and cons of each option for me?

The GP discusses the options with Jan and enters what was said into the record.

How do I get support to make a decision that is right for me?

The GP discusses the support that is available.

Jan elects for option 3. She is happy her symptoms are ‘not that bothersome to me really’ but is keen to try pelvic floor exercises and lose weight.

Appointment 2:

Four years later Jan has managed to quit smoking and has achieved a healthy weight. However, her prolapse related symptoms have significantly worsened (these now include urinary urgency, frequency, and voiding problems) and following unsuccessful attempts to insert a pessary she has been returned to her gynaecologist, Dr Khan, for a shared decision regarding prolapse surgery. The doctor utilises the NICE patient decision aid surgery for uterine prolapse, which Jan has been given to read in advance, to make a shared decision with her. Following the consultation, Dr Khan records the events in the electronic health record (EHR). She was impressed that Jan used the ‘ask 3 questions’ technique to help steer the conversation.

What are my options?

The doctor records what she told Jan about what generally happens for each type of surgery and what the operation involves. This included the option to delay the decision (option 2) or take no further action (do nothing).

- Option 1: Continue conservative management (‘do nothing’)
- Option 2: Not sure – schedule review.
- Option 3: Vaginal hysterectomy
- Option 4: Vaginal sacrospinous hysteropexy with sutures
- Option 5: Manchester repair
- Option 6: Sacro-hysteropexy with mesh.

Dr Khan records that Jan was invited to express her concerns and that she stated that her sister had previously had an operation for the same condition several years ago ‘that subsequently went wrong’. Jan had also heard ‘a lot of worrying things’ in the media about the use of meshes and tapes and specifically mentioned the outcome of the class action lawsuit in Australia. The doctor explained the differences between the sacro-hysteropexy with mesh (option 6) and the transvaginal mesh repair and reassured her that this procedure was not one of the options currently. She took the opportunity to raise some of the

uncertainties about option 6 based on her clinical experience and knowledge of current evidence.

What are the pros and cons of each option for me?

The surgeon records that Jan was told and understood that the general risks of surgery include infection, blood clots and back pain and that the risks from the anaesthetic would be discussed separately with the anaesthetist. The specific risks for each option discussed were also recorded as well as Jan's personal risk factors. She then uses the technique of positive and negative framing to discuss prognosis for each option and enters what was said into the EHR.

The doctor records that Jan was told (and was able to reflect her understanding back) the following about prognosis:

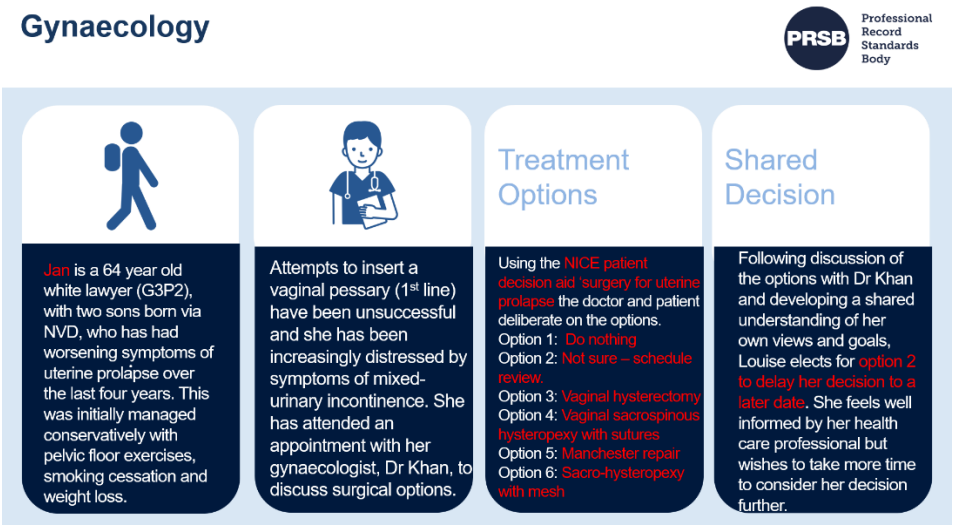
- For every 100 women who have vaginal hysterectomy (option 3), about one year after surgery on average 65 will say they had no symptoms and 35 will still have some symptoms.
- For every 100 women who have vaginal sacrospinous hysteropexy with sutures (option 4), about one year after surgery on average 55 will say they had no symptoms and 45 will still have some symptoms.
- For every 100 women who have vaginal hysterectomy (option 3) or vaginal sacrospinous hysteropexy with sutures (option 4), about one year after surgery 1 – 10 women found their prolapse came back and 90 – 99 did not.
- NICE did not find any studies that compared how well the other types of surgery worked (options 5 & 6).

How do I get support to make a decision that is right for me?

The doctor records that Jan was reassured about the support that was available and what was offered.

She also records in the EHR that Jan is still unsure and has elected for option 2, to delay the decision until a future date. She also uploads a copy of the decision aid that was used to the system.

Storyboard for appointment 2:



4 Children's Dental Case (storyboard)

Dental extraction: shared decision making

Professional Record Standards Body

Paul is a 10 yr old with Cerebral Palsy and visual impairment.
He has recently suffered from severe dental pain from a 'baby' tooth which has now subsided.
His parents want to make the right choice with Paul so the pain doesn't return.

Paul and his dad visit the dentist. A careful examination reveals a number of badly decayed teeth.
In discussion, the dentist chats about diet, prevention and the need to remove three teeth. They discuss consent and how the removal of the teeth can be achieved.

Treatment options

Although the pain has now stopped, Paul and his dad understand that this is temporary and that some treatment is needed. Due to the degree of decay, fillings are not possible so tooth loss is needed. The extractions can be either be carried out by simple local anaesthesia, with or without sedation, or under a general anaesthetic (GA)

Treatment decisions

Following the chat with the dentist, and taking into account Pauls medical history and his potential ability to cope due to difficulties with movement and co-ordination and the number of teeth needing to be removed, they opted for a GA. They felt reassured to have understood the alternatives, risks and benefits, in making their decision.

5 Colorectal Cancer (storyboard)

A process to aid decision making after surgery

Professional Record Standards Body

Jenny has just completed surgery for colorectal cancer. It has now been suggested that a course of chemotherapy would reduce the possibility of cancer recurring.
She is unsure whether to accept this additional treatment at the age of 83, and having already gone through a difficult operation three weeks ago.

She is seen by her consultant, Mr Jones, who had carried out the operation and continues to provide support to her. He helps her in treatment option choices based on the Benefits, Alternatives, Risks and the possibility of not having additional treatment (BRAN)

Treatment options

She learns that her operation had gone well and that her survival rate over 5 years is around 87%. In her BRAN discussions, additional chemotherapy will raise this percentage to 93%, but due to her frailty and other illnesses, and the possible side-effects, not having treatment would also be an alternative.

Treatment decisions

Having considered the options available to her, Jenny thinks about the potential improvements in her health, balanced with the difficulties presented by her individual circumstances.
In this instance, she feels that the small potential gain in health is outweighed by the potential effects of additional treatment and chooses not to have a course of chemotherapy.

6 Mental Health

Background

Postnatal depression is the development of a depressive illness following childbirth that is characterised by the core symptoms of major depressive disorder (as opposed to the emotional lability associated with the 'baby blues.'[23]

Vignette

Louise is a 26-year-old new mother who has attended the GP for her 6-week postnatal check following a successful normal vaginal delivery at term. She has brought along her new-born baby girl Emily, who is due for her 6-week baby check as part of the appointment. After declaring Emily fit and well the GP notices that her mother seems disinterested and proceeds to ask her questions about her mental health and wellbeing. These include:

- 'During the past month, have you often been bothered by feeling down, depressed, or hopeless?"
- 'During the past month, have you often been bothered by having little interest or pleasure in doing things?'

Louise appears unkempt and tearful as she describes how her symptoms started in the first week after birth with several 'highs and lows'. This included some sleep disturbance, weight-gain, and lack of energy. She says that following this initial period the highs have subsided, but the lows have become worse. She now feels tired all the time and tells the doctor that much of the time she feels extremely low in mood and has been unable to enjoy things as before - she has stopped breast feeding, which was previously especially important to her. The patient says that she hates herself for being this way around her daughter and feels very guilty about everything. She has insight into her condition and denies suicidal ideation or intent to harm her baby. The GP excludes symptoms suggestive of bipolar disorder or psychosis.

Louise scores 19 on the Edinburgh Postnatal Depression Scale (>12 has PPV 57%, & NPV 99%).[24] The GP orders some initial blood tests to rule out organic pathology including Full Blood Count and Thyroid Function Tests as well as a urine drug screen. She also provides safety netting advice and invites Louise to attend a next day appointment to discuss treatment options for her postnatal depression.

Appointment:

The GP invites her patient to discuss possible investigation and treatment options using the BRAN technique for shared decision making.

The GP discusses the following options and their risks and benefits:

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[23] BMJ Best Practice. Postnatal depression (2020). Postnatal depression - Symptoms, diagnosis and treatment | BMJ Best Practice

[24] *Op.cit.* PPV = Positive predictive value, NPV = negative predictive value.

- Option 1: 'Do nothing' – GP safety netting and signposting to mental health resources and organisations.
- Option 2: Facilitated self-help strategies (e.g., guided self-help, computerised cognitive behavioural therapy (CBT), exercise, sleep hygiene measures etc.) +/- referral for counselling +/- referral for CBT.
- Option 3: Sertraline (antidepressant SSRI), 25 mg OD (once a day). This drug has been shown to be undetectable in the serum of breast-fed infants.[25]

The patient and doctor agree to action option 2 and a trial of option 3.

Storyboard

[25] Op.Cit. SSRI = Selective serotonin reuptake inhibitor.

7 Multimorbidity

Background

Increased life expectancy is associated with a greater number of people living with long-term health conditions. Long-term conditions are those that generally require ongoing medical management over years or decades. Multimorbidity is defined as where a person has multiple long-term health conditions (whereas comorbidities are clinical entities defined in relation to an index disease and occur during its clinical course) – see figure 1.[26] Other problems that are distinct from but commonly associated with multimorbidity and which can complicate its management include disability, frailty, and the biopsychosocial factors associated with complex patients.[27] Older adult patients with multimorbidity may be relatively less likely to prefer taking an active role in decisions regarding their care.[28]

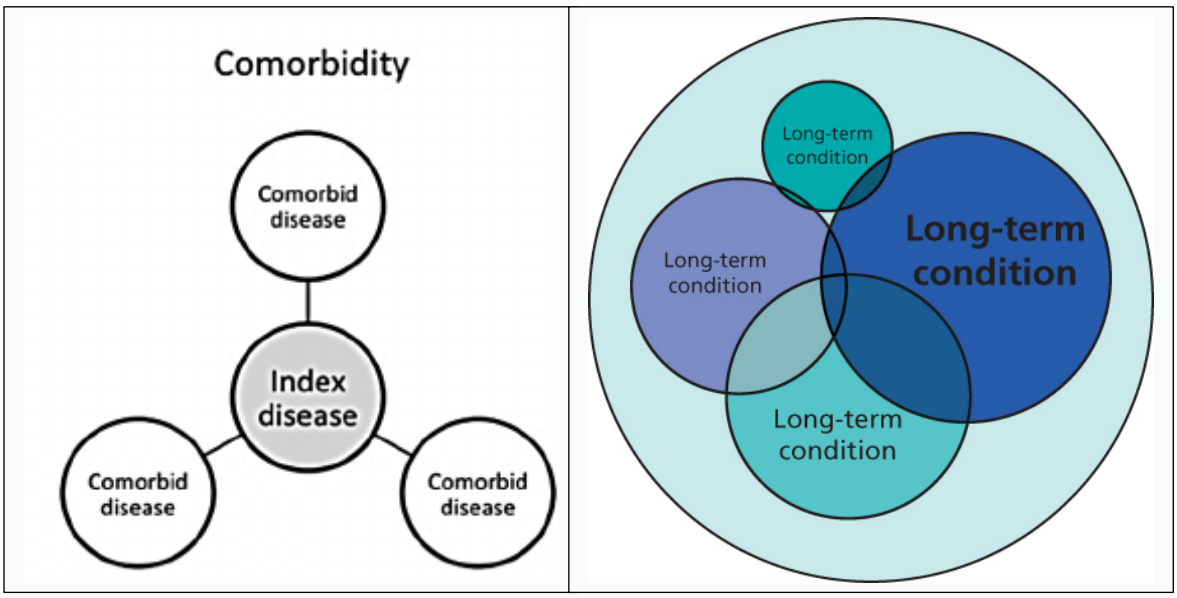

Figure 1: Comorbidity (left) versus 'multimorbidity' (right) (Adapted from Mercer *et al.* 2014)

Vignette

Andrei, a retired construction worker, is a 73-year-old man with multimorbidity and poor mobility. Following the death of his wife he has lived alone for three years in a second floor flat, where he has domiciliary care check-in visits three times a week.

He remains a heavy drinker and lifelong smoker with a 45 pack-year history. His other cardiovascular risk factors include hypertension, hypercholesterolaemia, and type 2 diabetes. Five years ago, he had a 'mild' heart attack (NSTEMI[29]) and has since had several

[26] Mercer, S., Salisbury, C., Fortin, M. (2014). ABC of Multimorbidity. BMJ Press. Wiley-Blackwell

[27] Manning, E., Gagnon, M. (2017). The complex patient: A concept clarification. *Nursing & Health Sciences*, 19(1), 13 -21: https://doi.org/10.1111/nhs.12320

[28] Chi, W., Wolff, J., Greer, R., Dy, S. (2017). Multimorbidity and decision-making preferences among older adults. Annals of Family Medicine, 15 (6), 546 – 551: https://dx.doi.org/10.1370%2Fafm.2106

[29] NSTEMI = Non-ST-Segment elevation myocardial infarction

percutaneous coronary intervention (PCI) procedures since then. Andrei has atrial fibrillation and 9 months ago had an stroke, which has left him with a mild right sided hemiparesis[30] and expressive dysphasia[31]. He has a history of recurrent falls. His CHA_2DS_2-VASc score for atrial fibrillation stroke risk is 6 (9.6% risk per year). 10 years ago, he was diagnosed with chronic obstructive pulmonary disease (COPD) and has been admitted several times over the years for acute exacerbations, but he is not on home oxygen.

Andrei presents to his GP with his carer, after she noticed he had passed offensive smelling black tarry stools in the commode this morning.[32] The GP contacts the local medical registrar on call and arranges urgent transfer to hospital, where he is admitted by the acute medical team. Andrei has no additional ALARM[33] symptoms and is haemodynamically stable. A Glasgow-Blatchford Bleeding Score[34] (GBS) is done:

Factor	**Result**	**Units**	**Reference range**	**Points**
Blood urea	6.8	Mmol/L	2.5 – 7.8	2
Haemoglobin	7.2	g/dL	13.0 – 18.0	6
Systolic blood pressure	119	mmHg		0
Heart rate	90	bpm		0
Other markers	Presentation with melaena			1
Total	**Score > 6 associated with 50% of needing an intervention.**			**9**

The registrar reserves Andrei a space on the first available elective list for endoscopy. Considering the history of this complex patient the doctor recognises that a decision point has been reached, where the need for an endoscopy & risk of bleeding is balanced against risk of stroke. He arranges for review by a stroke physician, who recommends starting Andrei on a direct-acting oral anticoagulant (DOAC).

The clinical pharmacist review's Andrei's medications. He is taking multiple medications including those for secondary prevention of ischaemic heart disease[35] and stroke[36]:

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[30] Hemiparesis = weakness or paralysis of one side of the body

[31] Expressive dysphasia = Difficulty putting words together to make meaning

[32] GPnotebook: Melaena

[33] ALARM symptoms include: Anaemia, dysphagia (difficulty swallowing), haematemesis (vomiting blood), melaena (passage of black tarry stools), persistent vomiting, involuntary weight loss.

[34] GPnotebook: Glasgow-Blatchford Bleeding Score (GBS)

[35] BMJBestPractice: NSTEMI - Prevention | BMJ Best Practice

[36] BMJBestPractice: Ischaemic stroke - Prevention | BMJ Best Practice

Medication	Dose	Route	Freq.	Indication
Ramipril	2.5mg	PO[37]	OD[38]	Secondary prevention
Bisoprolol fumarate	2.5mg	PO	OD	Secondary prevention
Clopidogrel	75mg	PO	OD	Secondary prevention
Atorvastatin	80mg	PO	OD	Secondary prevention
Metformin hydrochloride	1g	PO	BD	Type 2 Diabetes
Omeprazole	20mg	PO	OD	GORD[39]
Tiotropium/Olodaterol (2.5µg/2.5µg per dose inhaler)	2 puffs	INH	OD	COPD
Salbutamol (100µg per dose inhaler)	1 – 2 puffs	INH	PRN	COPD
Colecalciferol (10µg) with calcium carbonate (1.25g) (Calcichew-D3® Forte)	1 tablet	PO	OD	History of recurrent falls[40].

Shared decision point:

Professionals present: Medical registrar, Clinical pharmacist, Stroke physician.

Others present: Andrei and his carer.

The medical registrar leads the discussion and invites Andrei to discuss possible investigation and treatment options using the BRAN (Benefits, Risks, Alternatives, do Nothing) framework for shared decision making.

The doctor discusses the following options and their risks and benefits:

- Option 1: 'Do nothing' – Considering Andrei's informed understanding of the options and his wishes, hopes & goals.

[37] PO = *'per os'* (by mouth) ; INH = Inhaled

[38] OD = Once a day; BD = Twice a day ; TDS = Three times a day ; QDS = Four times a day

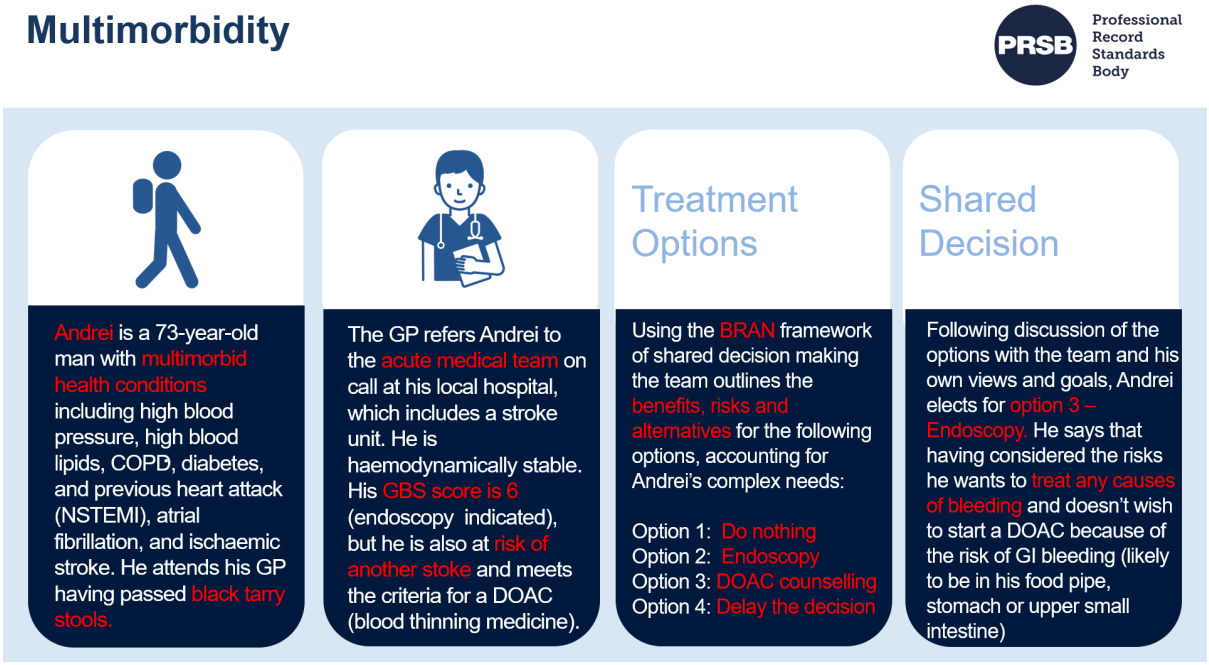
[39] GORD = Gastro-oesophageal reflux disease

[40] GPnotebook: Vitamin D and calcium supplementation in the elderly

- Option 2: Elective endoscopy +/- endoscopic therapy procedure within 24 hours of admission.[41]
- Option 3: DOAC counselling for consideration of DOAC therapy
- Option 4: Delay the decision – with Andrei's informed understanding of the risks.

Andrei elects to have the endoscopy declines DOAC. He says that having considered the risks, he wants to treat any causes of bleeding and does not wish to start the DOAC because of the risk of further GI bleeding[42]. He understands the risk of stroke.

Storyboard



[41] NICE: Acute upper gastrointestinal bleeding overview

[42] GI = Gastrointestinal system = Mouth, food pipe, stomach, small intestine, large intestine, rectum.

8 Genetic Condition

Primary Ciliary Dyskinesia (Kartagener's Syndrome)

Background

Kartagener's syndrome, a form of Primary Ciliary Dyskinesia (PCD), is a rare autosomal recessive genetic disorder characterised by the triad of dextrocardia / situs inversus, chronic sinusitis and progressive bronchiectasis.

The basic phenotype is a ciliopathy - defective structure and motility of cilia. Cilia are hair like structures, with a continual rhythmic beating motion, present on the surface of most animal cells. In the developing embryo, ciliary beating causes left-to-right patterning by directing flow of embryonic fluid and asymmetric activation of Nodal (a signalling protein). In a person's lungs, the 'mucociliary escalator' carries mucous containing microorganisms to the throat to be cleared (via swallowing or expectoration). Motility of spermatozoa is dependent on cilia in the tail. Defects to cilia in the above cases can cause the associated congenital reversal of organs, recurrent respiratory tract infections and male infertility.

The treatment for male factor infertility due to PCD is in-vitro fertilization (IVF) and intra-cytoplasmic sperm injection (ICSI).

Paul is a 22-year-old trainee welder with a 3 pack-year history born to non-consanguineous parents. He normally drinks 4 lagers a day after work. He was diagnosed with PCD shortly after birth. He has attended the GP to discuss quitting smoking and, after discussing the options, is referred to an NHS stop smoking advisor. At the end of the appointment, he discloses that he and his wife have been trying for a baby for one year without success. He is concerned that he may be infertile. They arrange a follow-up appointment to discuss this.

Appointment 1:

The GP discusses the following options and their risks and benefits:

- Option 1: 'Do nothing' - Conservative management with GP provision of lifestyle advice (including smoking cessation, reducing alcohol intake, maintaining a healthy weight and frequency of sexual intercourse) – recognising that not all men with PCD will be infertile and 98% of couples aged 19 – 26 will conceive within two years of trying. +/- Review in 12 months in line with the standard practice of waiting two years before further investigations or referral to an infertility specialist
- Option 2: The GP orders a semen analysis, which will inform Paul of his fertility status – recognising his background of PCD as a predisposing factor for infertility
- Option 3: The GP makes an early referral for specialist consultation to discuss the options for conception, recognising Paul's background of PCD as a predisposing factor for infertility (NICE CG156 1.2.13.7)

Paul elects for option 1 (with review in 12 months).

Appointment 2:

One year later the couple have been unable to conceive and Paul returns to his GP. The GP offers referral to psychological counselling (NICE CG156 1.1.2.3), signposts Paul to a fertility support group (NICE CG156 1.1.2.2) and discusses the risks and benefits of the following options:

- Option 1: Continue conservative management ('do nothing')
- Option 2: The GP orders a semen analysis, which will inform Paul of his fertility status
- Option 3: The GP refers Paul to a fertility specialist

Paul elects for a combination of options 2 and 3.

Appointment 3:

Following history and physical examination the urologist discusses the results of the semen analysis. Paul is found to have low sperm count and motility (his wife is fit and well with no known fertility issues). The clinician offers referral to psychological (NICE CG156 1.1.2.4) and genetic (NICE CG156 1.13.2.3) counselling and discusses treatment options – consisting of assisted reproduction techniques (ART) - including the possible benefits and risks of these:

- Option 1: Continue conservative management ('do nothing')
- Option 2: Intrauterine insemination
- Option 3: IVF without intracytoplasmic sperm injection
- Option 4: IVF with intracytoplasmic sperm injection – recognising that 'ICSI improves fertilisation rates compared to IVF alone, but once fertilisation is achieved the pregnancy rate is no better than IVF' (NICE CG156 1.13.3.1)
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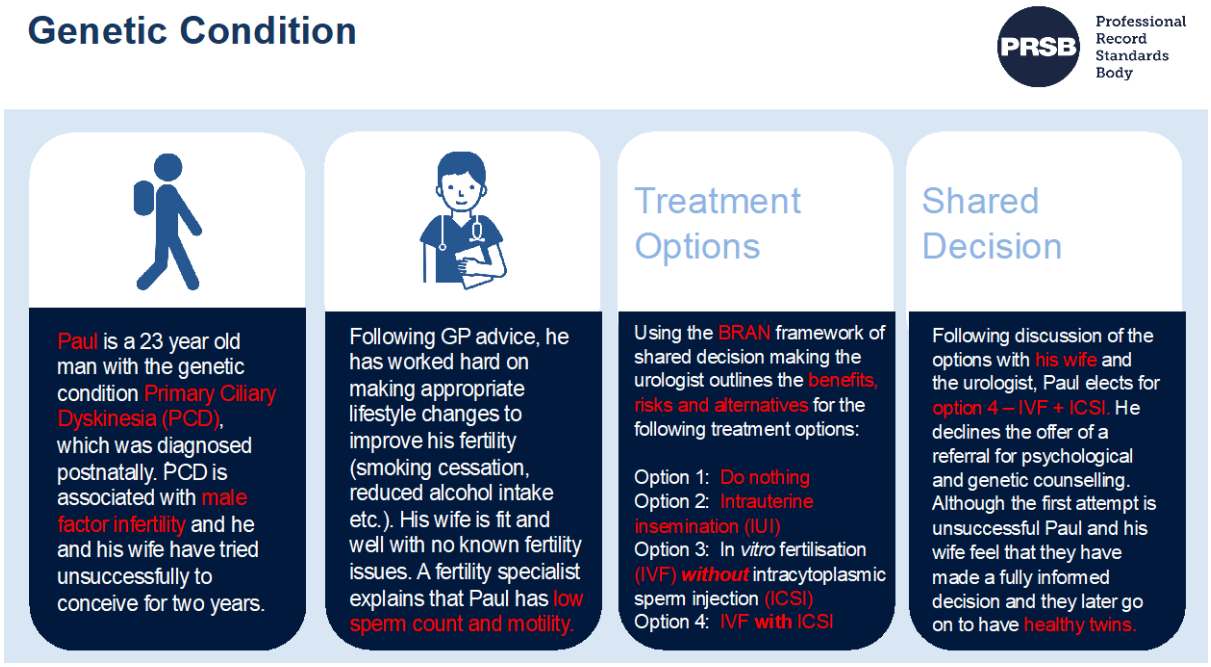
Paul and his wife elect for option 4. They agree and record a shared plan with the clinician.

Storyboard for appointment 3:



Sources

- BMJ Best Practice
- NICE Fertility Guidelines
- GPNoteBook
- PCD Family Support Group
- UCL Study
- Occupation & fertility
- https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3519024/
- https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5104509/
- https://bronchiectasis.com.au/physiotherapy/principles-of-airway-clearance/airway-clearance-in-the-normal-lung