**STOP-DEM – Deprescribing for People with   
Cognitive Impairment**

**Transcript**

**HP04**

So just like to start with quite an open question please. And just can you tell me about the care you provide to people with dementia or mild cognitive impairment, please?

HP04:  
Yeah. So I well in my role within a GP practice, I can conduct medication reviews and the group of patients that I was kind of focusing on is those with severe frailty. And so I don't specifically focus on dementia, but obviously some of the dementia patients fall within that within that group.

INT:   
Thank you. And how much of your workload is this?

HP04:  
Ohh like 20% maybe.

INT:   
OK.  
  
INT:   
And how many are taking multiple medications?

HP04:  
And lots but, but I'll of that 20% , do you mean specifically dementia patients?

INT:   
Yeah. Dementia or mild cognitive impairment.

INT:   
So of those, how many proportion are taking multiple medications?

HP04:  
Well, I only see the patients that are on multiple medicines.

INT:   
So yeah, so yeah, OK.

HP04:  
So my view would be skewed probably.

INT:   
Umm, what involvement do you have in their medication management?

HP04:  
So I would do like a structured medication review with patients that are on, yeah, multiple medications or have got severe frailty.   
So it's a case of going through the medications with the patient or the patient's care and literally making sure they understand what they're on and they still want to be on their medicines.

INT:   
Umm.

HP04:  
And then we have a discussion about stopping things if they don't want to be. Yeah, if they don't need to be on them or they don't want to be on those medicines anymore.

INT:   
Sure. And what are your views regarding deprescribing of inappropriate medication among people living with dementia or mild cognitive impairment?

HP04:  
And well, I think it's potentially more difficult in those what living with like cognitive impairment or dementia and or it's more and well it's more difficult because that that shared decision making is more difficult and obviously you can have that shared decision making with the with the family.   
But then they've got to make those decisions on the patients behalf. So I think it does make it more difficult and you've gotta make sure that you've got all the right things in place to make the decisions if the patient isn't capable of making those decisions themselves.

INT:   
OK. Thank you.

HP04:  
And that's the full another factor. Wait for the patients, Competent and capable of making those decisions themselves.

INT:   
Sure. Thank you. And any other advantages or on the other hand disadvantages or views around deprescribing within appropriate medication among people living with dementia?

HP04:  
Well, I guess they bought they've. They've normally got a carer or a family member that's kind of looking after them quite closely.

0:2:56.380 --> 0:2:56.660

HP04:  
So maybe in some ways they've got somebody else that we you, you can have that discussion with and it's not just one person making that decision, because actually sometimes with some of the older patients, if they don't have any a family network, they are making that decision on their own.

INT:   
Umm.

HP04:  
So, but normally with the with the kind of dementia or cognitive impairment patients there is that network already in place, but not always, but most it's more likely.

INT:   
So that the specific patience there, there's that there's a network there and how could some of those challenges you mentioned be resolved?

HP04:  
And well, I guess I guess it's making sure that network is in place and I know we've got like dementia care navigators in our area, but I just don't know whether they're used enough.

INT:   
Mm-hmm.

HP04:  
And I often think that they people don't seek help early enough and don't know that those kind of services exist is probably one of the.

INT:   
With the dementia can good.

HP04:  
Yeah, that's probably one of the things that I would I would kind of say that we still need to get the message out that actually those, yeah, there are dementia care navigators in our community that can be supportive. And I think I think we end up referring patients quite late on when they're really struggling and actually be better to get those things in place beforehand.

INT:   
Thank you. And what types of medication would you feel most comfortable deprescribing for people living with dementia or mild cognitive impairment and why?

HP04:  
I think that varies significantly because it really depends on what the patient's priorities are.

And I mean, there are obviously some that perhaps are more are more easy to and the deprescribe like you might think things like statins that don't that you're talking about are kind of longer term

benefit. And actually, if a patient's forgetting to take the medicines, then that might be it might be easier to stop those kind of things and concentrate on the ones that really.

HP04:  
Yeah, that really matter.

INT:   
Mm-hmm.

HP04:  
But then I also think that I like to think that we I would like to try and stop ones that have a high anticholinergic burden school, particularly in dementia patients, because we know that the anticholinergic burden school can increase the like memory loss.

HP04:  
So, but those are often the ones that patient doesn't want to stop, because they're often things like antimuscarinics for bladder symptoms. And actually, patients often find that that's actually one of their main concerns. So sometimes they're really reluctant to stop that. So what often what I want to stop is not necessarily what the patient's priority is. So that conversation can be more complex.

INT:   
And what would help you in that conversation?

HP04:  
I think more resources for patients for them to be able to understand the risks in a kind of patient friendly way and I think some of the stuff I've talked about previously is resources. When you start a patient on a medicine that it's like it would be really nice if there was just a suite of that very self explanatory leaflets that explained the kind of longer term risks.

Particularly, I think when you're talking about anticholinergic burden, two patients in a simple form so that they can make an informed decision, but probably not at the point where you're trying to stop it. It's really about at the point where you're starting that medication.

INT:   
And on the other hand, what types of medication would you be reluctant to deprescribe and why?

HP04:  
Well, I think it's more difficult, right? Obviously, when you've got things like this Yeah, that. Yeah, that that clearly we would need to carry that on or we would need to have a very yeah, a much more complicated conversation if we were gonna think about stopping things like that.

And I think diabetes medications a bit more complicated, but we can be a lot more and we don't have to be so strict in the kind of severe and frail patients. So it's yeah, it's often more difficult to have that conversation about stopping diabetes medication, but actually we've got a bit more guidance on like what their HBA 1C can be. So it can be a little bit higher in those kind of patients.

HP04:  
So actually probably some of them that are on those kind of medications don't might not necessarily need to be on them. We can kind of be a relax their medication rating a little bit more, but yeah, you know, there were obviously and like I mean anticoagulants are pros probably are another example and I quite often have conversations with patients about stopping anticoagulants. So some people, for some people that's. I mean, yeah, that's a very difficult conversation to have and it is a very difficult conversation, but I think we know the risks and benefits and actually, but that's hard for the patients to understand. So yeah, and ultimately that one has to be like a shared decision.

INT:   
Yeah, anticoagulants. And what would be the reasons for you to not support reducing or stopping a medication?

HP04:  
That's a good question and.

INT:   
Take your time.

HP04:  
Why would they not? I don't know that I ever really I am. I am more of a probably a more of a deprescribing person than I am encouraging. Especially as patients. Yeah, especially for patients with dementia, that would probably struggle with their medicines. And the older kind of frail population that, I mean, if a patient doesn't want to stop their medicines, then obviously I won't be causing them. But they're often struggling, and they're often asking for your kind of professional opinions.   
So I probably do sway more towards actually I would say that you can probably stop some of these medicines. But yeah, I wouldn't like you.

HP04:  
The only time you probably wouldn't wanna stop, I would probably think about not stopping them as if they're really gonna get symptom benefit from them. Because obviously I don't want the patients to become and that's the main thing with the ‘fibroxin’ is I don't want them to be symptomatic. I don't want them to be tired all the time and have all the other symptoms of thyroid problems. So yeah, that would probably be the main reason why.

INT:   
OK.

INT:   
Thank you. And what are the main things that you think need to be in place for successful deprescribing for someone with dementia or mild cognitive impairment?

HP04:  
decision making. And I guess resources like I've already said.

INT:   
Here any specific results support network.

HP04:  
And what I think and that's support network because yeah, because it's hard to make that decision on your own. And actually, even if I mean, even if they've not got relatives that will support them, even if they've got a, like.

INT:   
Umm.

HP04:  
Yeah, like I said, a dementia care navigator or even just carers that somebody else that they can have that discussion with. If they're at that stage where they can.

INT:   
And I know we touched on this a little bit at the beginning, but if you could describe your experiences of having deprescribing discussions with people living with dementia or mild cognitive impairment or their informal caregivers?

HP04:  
This is where it's probably more difficult because I still do a lot of my consultations over the telephone and actually I think I'm probably not …. Say and therefore it's. It's difficult to understand how much impact, like problems of impairment the patient has with.

INT:   
Uh-huh.

HP04:  
Obviously you can look at their records and see whether they recorded with dementia.

INT:   
Umm.

HP04:  
You can look at their drugs and see whether they've got a dementia drug on their record, but trying to gauge what kind of level they are and is quite difficult. And actually, sometimes you get, sometimes you ring and you get the carer straight away.

HP04:  
And I have had a situation where I have spoken with a carer and gone had quite a few conversations with the carer that doesn't necessarily seem to be managing the patients medicines particularly well and realise that actually I haven't actually spoken directly to the patient. So I might have just made an assumption that the patient hasn't got capacity, but because on the phone I've never had the patient and it's always the career that kind of intervenes and speaks. And so actually, sometimes it can be really difficult to try and actually reach the person and try and assess whether they are and yeah, whether they have capacity to be able to make their own decisions. And I also find that's not very well documented either in.

INT:   
Umm.

HP04:  
It's not very well documented in secondary care to be honest, because sometimes we have patients that we're kind of on the verge of have they got capacity to make a decision and then we're like, oh, it's great. They're in hospital. Hopefully they'll help us with that bit. Nope, they come back out of hospital. You'll still like, right? No more information on that.

INT:   
Right. OK, well, how.

INT:   
How do you how do you kind of address those situations?

HP04:  
Well, I mean the one the, the, the one that I had more most recently actually ended up being a safeguarding situation. So because I actually did try and speak to the to the patient and I could not get the carer to let me speak to the patient and actually this patient was in an out hospital. So I spoke to the hospital and we actually did read to safeguarding concern about this patient. So it can be really difficult and I think generally I think now I make an attempt to talk to the patient.

HP04:  
I'm so even, even if it's over the phone. So I so it so I think from that example it's just made me more aware of the fact that yes, actually I'm I might have consent to talk to the carer and that's what we would check is that we have got recorded consent to do that.

INT:   
Umm.

HP04:  
But I will still try and at least have a conversation with and in some situations that might not be possible. And actually I then have to feel that actually if I've got consent and the carer seems to be acting in the patients best interest, then that's fine.

INT:   
OK.

HP04:  
But yeah, I think that's made me a little bit more conscious just from the, from the experience I've had that actually I should, we should really try and talk to that patient. But I'm and actually maybe I should be doing more things face to face, and I would. Do I would do face to face if I felt that I wasn't able to and to obtain the information I needed over the phone. But I think in some of these situations the patients are also housebound, which makes things more complicated because yes, I can go and do a house band visit, but that's much more difficult to organize.

INT:   
So there's other considerations there.

HP04:  
Yeah.

INT:   
And in terms of that case.

HP04:  
Yeah, it was fun.

INT:   
Sorry, was it a family carer or more formal carer who's involved normally care.

HP04:  
It was a family carer, yeah.

INT:   
And thinking about those, those kind of challenges you, you mentioned there so that the telephone and then also the secondary care and then the kind of linkage with secondary care.

INT:   
What would maybe help those situations for you, I know we've touched a little bit on that, but anything else that.

HP04:  
Well, I mean better communication between primary and secondary care would be great.

INT:   
Umm.

HP04:  
So you, I mean I have got a secondary care background,

INT:   
Umm.

INT:   
Umm.

HP04:  
Before I worked in primary care so and I and we really don't have any links and I probably make more links than anybody else would because I know some of my colleagues at work in secondary care. But even then we have no like yeah, I mean, sometimes I will ring secondary care like when I know a patient 's been admitted if I've been working with the patient for a while in primary care doing like medication reviews.

INT:   
Umm.

HP04:  
I will often ring the board if I know that that patient has been admitted and just say can I speak to the pharmacist? Can we and have a conversation about what we've been doing and can they carry on the same things in hospital and like, can they help me with some of the other bits?

INT:   
Mm-hmm.

HP04:  
But that doesn't happen very often, and it would be much better to have those kind of more consistent links.

INT:   
OK.

INT:   
So that that moves me onto what would what would work well or help the facilitate those conversations you mentioned there about the links and phoning ahead is there anything else that you think might help that?

HP04:  
Well, I don't think we have a very good network structure in our local area. So I'm we like we don't have like an older person's consultant, particularly like a or a like a frailty team a particularly well known.

HP04:  
I think we've got like little pockets of people that are doing work, but we don't have like 1 nice, like we don't have a structure in our PCM for example that we have like a kind of geriatrician or like old person's mental health that we can kind of go to. We can make a referral and they send us back information, but we don't really have like an MDT structure which would probably be something that would be really good going forward.

INT:   
That that MDT structure also mentioned about point of contacts as well, yeah.

INT:   
OK.

INT:   
And anything from your conversations on the telephone or that that you've sort of worked well, any anything that you but the experience of that you thought that that worked well?

HP04:  
I think it's about giving patients information. So I had a I've got. I've had in fact had a patient yesterday where I was talking to and I was actually talking to the patient's son and. Yeah, and his dad does have dementia, and they were, and wanting to, it was actually the family that had contacted us, wanting to kind of review his medication. But actually he didn't wanna make any decisions. But he wants me to give him the information so that they can then get. They can then go and talk as a family and then I put them back in to come back to the discussions and I think I've done that a few times now and I think that works quite well.

INT:   
Umm.

HP04:  
Is like I'm gonna kind of lay out all of my thoughts and they're gonna talk as a family, and then we're gonna come back to that conversation. So it's not like I didn't have. I didn't do it face to face. I was on the phone, but actually I've then just gonna present them with my thoughts and my kind of these are the things that I think are. Easy options for deprescribing. Let's start with those and then there are more complex things. So this patient wasn't an anticline and I said, well, that's a more complex decision and but I think they originally came to me because the community pharmacist had mentioned that they might be on the wrong dose of anticoagulant. They aren't on the wrong dose of anticoagulant, but I was like this can start the conversation of actually well, do you still want your dad to be on an anticoagulant? And I kind of explained the risks and I said to him don't need to make a decision now. I'll send you lots of information. I'll give you all the information for the other medications and he was really grateful for that because he said that great, I can go and talk to my sister. We can talk together and we can make some decisions about treatment, but I haven't put them on the spot.

INT:   
OK.

HP04:  
And they've got time to think about it, and we can come back and compare.

INT:   
Umm.

HP04:  
So I've done that a couple of Times Now, and I think also following up appointments. So I do a lot of like obviously describing takes a long time and it's not just done in one appointment. So it's so. So I'm always saying to patients, right, so we'll try. We'll try stopping this and just because we're stopping it doesn't mean it can't be restarted. And then I'll follow them up in a few weeks to make sure that they were happy with that being stopped. And if they aren't, then they can restart it. Yes, I think I think it's about having those kind of.

HP04:  
Yeah, that security blanket for the patients to know that actually we're not stopping something, forgetting about them. We will be coming back to review it again, yeah.

INT:   
And who do you think is best place to be involved in deprescribing discussions in primary care for people living with dementia?

INT:   
Mild cognitive impairment.

HP04:  
And well, I think pharmacists because we're the ones that have more time to do it, say I mean there are some, there are some brilliant nurses as well and that I know that I know there are some really good like frailty teams in primary care that will do some deprescribing. So, but I think I think for them, it's about having the having the structure, but even for pharmacists, it's about having the right skills and the right knowledge and it's not right. I mean, we've got quite a big team of pharmacists in our practice, but not all of them will be comfortable with deprescribing.

INT:   
Umm.

HP04:  
So it's just because I've got years of experience and one of my other colleagues is very similar. She she's quite happy to do a do deep scribing but for the others. It's yeah, they don't find it as easy. So yeah, but I think pharmacists are very well skilled to do it.

INT:   
Umm.

HP04:  
I just don't think the GPS have the time, so to look through the information and yeah, I mean some of I guess there are some GP's that that again have a real interest in it then that's fine. But I think for the for the, yeah, for the general standard GP, I would have said they were they are more than happy to hand it over to a pharmacist to spend more time on it

INT:   
And are there any professional groups you think should not be involved?

INT:   
Umm.

HP04:  
So within our practice, that's obviously our like Advanced nurse practitioners.

HP04:  
But again, I think some of those might kind of specialize more in in frailty. So I don't wanna kind of rule them out as a group completely, but I think it needs to be.  
It needs to be part of their role and not just something that comes along. Comes as part of the kind of urgent care consultation, because that's probably not the appropriate time and probably some of the newer roles like you're kind of paramedic type roles that and I think there are there are some paramedics that are going out into the community and kind of reviewing patients and I guess it depends on whether they're doing that from an urgent care perspective or from a they are the person that is seeing those really severe frail long term condition type patients.

INT:   
Umm.

HP04:  
So I think it, I don't, I wouldn't necessarily rule out a person like I think it depends on how they're working and what their, yeah, what they're kind of slant is because actually yeah. And like when I'm doing because we end up with a with quite a bit of kind of sort of reactive work. So we end up with like, yeah, like answering Econsults all the time.

HP04:  
And I wouldn't fit my deprescribing into a kind of Econsult type conversation.

HP04:  
That's a completely different thing. You would answer the question that the patient wanted there and then and I would book them in for a separate appointment to do. Yes, I think it, yeah. So perhaps wouldn't rule out a specific person, but it's the kind of context that they're working with in.

INT:   
So it's kind of.

HP04:  
Yeah, I'm just trying to think if there's anyone else I really would say wouldn't shouldn't do it.

INT:   
Umm yeah.

HP04:  
I don't think so, but yeah, I think it's just more about that person's training and like, yeah, I mean, there are so many new roles coming about at the moment that but by.

HP04:  
But yeah, I still think it's about the training and the context that that person is working in.

INT:   
Taking into consideration, as there's other factors beyond the professional group as such as well, yeah, OK.

INT:   
And in terms of leading the discussion, do you have any thoughts on who is best to lead the discussion about deprescribing discussions in primary care for people living with dementia?

HP04:  
That's that is an interesting question because I am more than happy to lead that conversation as a pharmacist. But I think there are some circumstances where perhaps that initial conversation is better coming from a GP, and I think that's obviously particularly when you've got a patient that's built up a rapport with their GP and actually they don't like to hear that message necessarily from a pharmacist for the first time.

INT:   
Mm-hmm.

HP04:  
I'm and actually they. Yeah, they might like to just hear the message from a GP 1st and then they'll be more on board with anybody else making those recommendations. And so actually that does sometimes work a bit better if the GP kind of plants the first message of. Well, I don't actually. You're on a lot of medicines. Maybe we'll refer you onto our pharmacist team to review some of these medications and see if we can, if we can stop any of these things. And I think actually sometimes that yeah, that does help provide the message. I mean normally once I start a consultation with the patient, they haven't got a problem with the deprescribing or when they realize actually how much information we can give them. But yeah, there are. There are those situations, I think sometimes where a patient's got really good rapport of the GP and they don't want to do things unless they're GP tells them so, yeah.

INT:   
That kind of relationship aspect, yeah. OK.

And are there any occasions when it when it is or when it's not appropriate to involve patients in those deprescribing discussions?

INT:   
And specifically of people living dementia

HP04:  
Well, it's more difficult, isn't it? Because they haven't got the capacity to make and make the decisions. Then it. You can't really involve them, but that's when you need to involve the carer or who have or. Yeah, all the family member that is making those decisions with the patient, it's, yeah, it does make it more difficult. I'm by do is try and involve them.

INT:   
Mm-hmm. OK.

HP04:  
But I think yeah, it is more difficult because they are not always in a situation where they can make decisions.

INT:   
And in terms of UM, when it's easier when it's not appropriate to involve informal caregivers as well, do you have any thoughts on that?

HP04:  
Like as in family members. Well, I mean in that example that I was talking about earlier, it was really difficult because that family member, we don't feel was making the best decisions on the patients behalf. So I think then it becomes very difficult to and to do what that carer would they think they're doing the best thing for the patient. But actually in our professional opinion, we don't feel they are doing the best thing for the patient and then it becomes really difficult and actually we've in this kind of situation in the situation in that example, we almost can't use that carers opinion because we yeah, because we don't feel they are making the best decisions for the patient and it's very difficult because the patient, yeah, can't really   
HP04:  
And we kind of have to go with what we feel is best interests of the patient really.

HP04:  
So yeah, so that so it can be very difficult when you when you think that the carers not making the right decision for the patient, that doesn't happen very often.

INT:   
Umm.

HP04:  
So a lot more of my conversations are not like that.

INT:   
Umm.

HP04:  
And yeah, and I normally completely agree with the decisions that are being made by the carers with the patients and myself. But yeah, we just have this one particular patient that is, yeah, that there is an example of where actually I can't trust what the carer thinks. I don't think the carer is doing the right thing for the patient and then it makes it very difficult.

INT:   
I see it's called yet, and so on.

INT:   
On the whole, in terms of involving informal caregivers, what is it?

HP04:  
Yeah. I mean, I think from the whole it's much easier when it's a family member.

HP04:  
I'm or. Yeah, as a as a carer, it's more difficult when it's structured.

INT:   
Umm.

HP04:  
Caregivers or like external caregivers because it's more difficult to have that kind of conversation.

HP04:  
But then it does vary so much.

HP04:  
I've had some really good conversations with kind of non family member carers that completely understand the patient have been their carer for absolutely years and actually like, know the patient better than like anyone in the GP practice does. So it does vary considerably, but then you'll have others where you're trying to get hold of that patient's carer and you'll just get put through to a like the care agency who, who and the person you're speaking to doesn't know the patient at all and well and. And yeah, and therefore it's very difficult in those kind of circumstances.

INT:   
Thank you.

INT:   
And what would assist engagement with health and social care colleagues to support shared decision making?

HP04:  
Again, just more working together I think, but just maybe he's got time to be doing that.

HP04:  
Is the problem, isn't it time, yeah.

INT:   
Is that across primary care and secondary care?

HP04:  
I think so. Yeah.

HP04:  
So I mean, sometimes when a patients just, well quite a lot when a patients discharged from secondary care, sometimes we don't even know where they've been discharged to, it's that bad.

INT:   
Alright.

HP04:  
But like, if they they'll sometimes you're like because we do all the discharge summaries in our surgery and as far as the pharmacy team, sometimes you'll read a discharge summary that the discharge will address will still say it's their home address and you'll read all the information and then you'll see a line in the information that says patient discharged to care home and you're like, OK, where's this patient gone? That's the literally the one line that we've got cause and so like, so even that basic communication is often not there of actually like obviously the person that's on the ward completely gets where this patients go into.

INT:   
Thank you.

HP04:  
They've had all the conversations with social care, etcetera, don't really get the fact that no one's informed the GP surgery or where this patient's gone to. And it's terrifying. Sometimes when you try and ring that patient and then you might, and then you might get a relative that picks up the phone because that might be whose numbers actually on there and you're kind of saying, well, can I speak to the patient? And they're like, oh, they're yeah, they're in this care home now you're thinking. Great. I didn't even know that piece of information. It doesn't. It doesn't look good that we can't coordinate our communications.

INT:   
Yeah, that that so that communication seems quite key.

HP04:  
Yeah, like and I think, yeah.

HP04:  
So even from the basic so we can't even get, we can't. So we don't even get the basics right of like where the patients gone, let alone like what we might, what might have been discussed about their medication. They yeah, we've got all the way to go.

INT:   
OK, that's what the communication, OK.

INT:   
And what would assist engagement or involvement of patients living with dementia, mild cognitive impairment and all their informal caregivers? I'm thinking more family members here in the deprescribing process.

HP04:  
Yeah, we'll probably knowing that they can even access like the people that they can access, most of them don't know, like they don't know that there's a pharmacist that's at the surgery. So they don't know that that resource exists. They don't really know what we do within GP surgeries. Say I'm yeah.

HP04:  
So that's one thing I think just knowing who they can contact in the surgery, full stop, even if there's not a pharmacy team, I think it's not. t's not easy for patients to contact primary care when it's not like when it's not an urgent issue, because we don't have the time and as much as we'd like to not be focusing on urgent stuff.

Unfortunately, that's the way it ends up in the current climate. Is it's very hard to do. I mean, we do still do our try and do our kind of formal annual reviews, but I think without like people probably are used to that kind of structure and don't realize that they've got an opportunity at other times to be able to approach the practice and say actually can I have a discussion with someone about stopping my medicines. I think we need to empower the patients and carers to know that they need to be asking those kind of questions.

INT:   
Thank you.

INT:   
And what would facilitator, sorry.

HP04:  
And the problem I guess I guess the problem of part of that is that it's not.

INT:   
Mm-hmm.

HP04:  
It's also not consistent across primary care either, so you can contact my surgery and you can get a lovely pharmacy team, but you might contact another surgery and they don't have a pharmacy team and you might not have GP that's got any expertise in that or a nurse that's got any expertise in that. So it's very, yeah, so the message that we give can't is difficult to make that consistent message when the staffing across primary care is not consistent.

INT:   
OK.

HP04:  
I guess it's the problem.

INT:   
OK.

HP04:  
Yeah.

INT:   
So that that kind of resource issue and then different kinds of resources I'm hearing in in different organisations and then that consistency and linking up between those as well and the communication and the.

HP04:  
I mean, yeah, I mean, and that that is that gives another example as well because our GP surgery, our PCN, works across two different areas.

INT:   
Mm-hmm.

HP04:  
So because I was saying to you like so we've got an say a .....postcode which sits in …..city, we've got an ... postcode which sits in (name of county). HP04:  
So we have to refer to different places depending on where the patient's address is, so they're all sat on one GP system. But we have to look and go. This patients in …. (city name), this is the service that we can refer to this patients in ….(county name) So in …(city name) .this is the service that we can revert to.

HP04:  
So even for us the message is not consistent, and we've gotta think what area is this patient from?

INT:   
Yeah, that consistency then.

INT:   
And what would assist engagement or involvement of patients living with dementia and mild cognitive impairment and all their informal caregivers in the deprescribing process.

HP04:  
Now I think we really talked about that. Haven't we like having resources when they started the medication?

INT:   
Yeah.

HP04:  
Understanding the, you know like the side effects of medication from the beginning, because actually like some of these, yeah, some of these medicines have side effects that can increase the risk of dementia that that should be that patient should be told about like way before they're at the dementia point. And I yeah, sorry. I asked the tell me the question again.

INT:   
It was about assisting engagement or involvement of patients with dementia or mild cognitive impairment and all their informal caregivers in the deprescribing process. Anything that can assist that?

HP04:  
Well, well, also I think having maybe having a bit more of like support in the Community. So and so I know like I mentioned that we have got the dementia care navigators, but again I know that resource exists. I actually know what they do. I don't meet them so because and I don't know whether they have a network of whether they encourage deprescribing because, yeah, is. Yeah, it's not great for people that I have specifically met and found out. Like what they do, we were told they exist and that they are really good support for people. So we refer patients to them, but actually we haven't got a kind of. Community group that we can go well, actually this is this is where we could give you the support.

INT:   
And what would facilitate good communication with patients living with dementia?

INT:   
Mild cognitive impairment and all their informal caregivers in the deprescribing process.

HP04:  
Well, again, I think just having like here structured resources and standard like start, yes, standard information that you could give to people that and if everybody gives the same message, I'm having the same issue with other kind of non just related to dementia patients. We're doing some liquid work at the moment and I'm like, how can we make sure that everybody gives the same message. There's so many things out there, but actually we wanna make sure we're all using the same thing because it's not good if one healthcare professional says one thing and then someone else uses a different resource and says something different.

HP04:  
And that's where it's like sometimes having too many resources is not a good thing because you want to all be using the same thing and not confusing the patients and the carers with different messages from different resources.

INT:   
What language should be used to in communicating information about medications with people with dementia or mild cognitive impairment and their informal caregivers.

HP04:  
Well, the same language that we should be using for any patient, really, I think I don't think we should be treating them any differently. But I think often we use language that's too complex for the majority of patients in the 1st place, but think half average reading age in England's about 9, isn't it? Or something really, really low and actually quite a lot of the information that's produced would be very difficult for. So I think our average population to understand that, I don't think we should be treating those with dementia or their careers or giving them different information or different level. I think often it's too complicated for our normal patients as well.

INT:   
Less complex complicated in though.

HP04:  
Yeah, I don't think that's necessarily give just for patients who have dementia. I think for our kind of general population, I often look at things I we were doing some work on. We are doing semantic argument work at the moment and I looked at that information. They fit that this company had written to, sent to the patients and I thought ohh for our patients are not going to understand this.

INT:   
History.

HP04:  
I had to take out some of the wording and just change some of it. They were like, yeah, that's fine. And I was thinking, yeah, like that I think people often don't think that. And actually interestingly, we did some hypertension work with the community quite recently and we had someone from the voluntary services come in.

HP04:  
And the first thing he said is, can you stop using the word hypertension. Cause, but I'll patients don't understand that. And I was like, yeah, that's just so interesting.

INT:   
Yeah.

HP04:  
We're just on a completely different level save and it's very difficult as healthcare professionals not to revert to medical terms. So yeah.

INT:   
Yeah, we'll be looking at the not assumptions, but their professional language that's used and different perspective and how do you feel about engaging patients with dementia or mild cognitive impairment is shared decision making as part of the deprescribing process.

HP04:  
Like I said, it's difficult because yeah, I think I would always try and make sure that the patient was involved, but it's difficult to know like how you know what capacity the patient has to make that decision. And if you're just talking about the patient, I think it's more difficult to have that shared decision making. But I think it's important to try and to see if you can kind of have that conversation with the patient. But obviously, if the patient clearly doesn't understand and then that's when I would then move on to having that conversation with somebody else on the patient's behalf. But yeah, I think we should always try and involve them, but I think it's more difficult.

INT:   
And what might help, or might help facilitate their involvement in shared decision making.

HP04:  
Well, I mean, I guess it's all about consistency again isn't. It just I mean consistent way of us knowing whether that patient is capable of being involved in the decisions like it would be lovely. If I could just log on to the GPS system and there could be a note that says this patient has dementia.

INT:   
Umm.

HP04:  
But they're perfectly capable of making their own decisions, or this patient has really severe cognitive impairment and actually can't make decisions and that like I real clear message that you don't have to think and you can kind of go well, actually, OK, I know it's not. I'm not even gonna need to try and I'm not going to try with this patient, but then they'll always be those kind of in between cases.

INT:   
Umm

HP04:  
But if you knew that there was a kind of you must like a grading system, I guess, which would be very difficult to determine. But yeah, I think from my perspective, actually that would be quite that would be quite nice if I can go well this patients on a dementia drug therefore they've got or they're on the dementia register actually. Where can I find that assessment? Because normally you're like, you know, it's fair that where to find out if that patients got capacity, it's digging through the GPS system trying to work out who's if anyone recorded it or not.

INT:   
Some kind of capacity statement to inform those decision making discussions.

INT:   
Yeah, yeah.

HP04:  
Yeah, which ideally really should be something that's recorded like for secondary care to access as well. o it's like it should be a kind of summary care record type thing that's like. And when?

HP04:  
So when hospital make that decision, it's clearly on their summary care record, which then transfer back into the GP surgery. So we don't have to have the same.

INT:   
Mm-hmm.

HP04:  
Everyone doesn't have to have the same conversation or the same thoughts, and you can go well, actually I know exactly where I would look for this and if it's not there, you know it's not been done.

INT:   
Umm.

HP04:  
Whereas now you're just like, well, has it been? Has it not been done?

HP04:  
Who knows.

INT:   
Again, consistency in in in communication is not that of that message on.

INT:   
And how do you feel about engaging informal caregivers of patients with dementia and  
mild cognitive impairment and shared decision making as part of the deprescribing process.

HP04:  
So it depends, I think, whether you're talking in a formal caregiver, that's a patient's relative or a formal caregiver that's part of an agency. Because again, I think that just stems back to what I've said previously that actually like if it's a family member, then that's easier.

INT:   
Umm.

HP04:  
I think because you kind of know that that person will know that patient, but when it's a. Yeah, I'm a formal care agency.

HP04:  
It's difficult to know how well that carer understands the patient and like I said previously, that could be it could you could have a career that really, really understands that patient and then you're more than happy to involve them in the discussions that actually you could just have a patient that has a different carer every week or every day. So, or they could just be a new carer and they don't really know the patient. Therefore, it's very difficult to get them involved in those discussions and that four, I think it's more difficult to make those decisions.

INT:   
OK. Thank you.

INT:   
And what tools are resource and resources are needed to facilitate shared decision making in relation to deprescribing for patients living with dementia or mild cognitive impairment?

HP04:  
Well, I'm I think I still, I mean there's a generally a lack of tools in the 1st place for deprescribing and but there are there are like some good resources that we that I would currently use. So there are like some patient decision aids and we quite often now use GP evidence, which is a very good website with. I mean, there's quite a few decision aids on there. They are more healthcare professional related, but I do sometimes use those with … as well because they are a good resource and there are we have other websites like Pre-script that we can use like kind of deprescribing information from.

HP04:  
I don't think I would use the information different for patients with dementia than I would for any other patient. Think there's generally a lack of kind of deprescribing resources, but I don't think I necessarily think they should have different. Particularly, particularly when you're comparing like some with severe frailty and dementia, I don't really see them as particularly different.

INT:   
OK. Thank you.

INT:   
And any other thoughts around how umm, patients living with dementia or and their informal caregivers could be supported during the deprescribing process?

HP04:  
Well, I think it's about having those follow up appointments and making sure that you're kind of giving them an opportunity to the same as I would any other patient is like, yeah, if we're if we're stopping medication, we always say it's a yeah, this is a trial.

INT:   
Yeah.

HP04:  
We can restart medicines and so yeah, I don't think it's any different, but I think that follow ups important for any patient and then to know where to come back to. So we would always say to the patients, obviously we'll book in an appointment, but if they need to talk to us sooner and then they just contact the surgery. So I think it's giving them that reassurance that and I think that makes deprescribing more successful if they've got that reassurance as well and the follow up booked in.

INT:   
Thank you.

INT:   
And who should be following up patients?

HP04:  
I was gonna say whoever started it, but actually, maybe not. Because sometimes the GPS do have the initial conversation might start a reduction and then pass it on to the pharmacist within our surgery to carry on, which I don't have an issue with. I think that's absolutely fine and that works quite nicely done.

HP04:  
Often if the GP's have the initial conversation and then pass that on to our team to kind of continue, and I mean I wouldn't necessarily, it's I think it's good to keep it with the same person. So but, but that doesn't always work because like I've I'm going on holiday next week and I've had to hand over a patient that I'm in the middle of describing to one of my colleagues.

INT:   
Umm.

HP04:  
But I've told the patient that that it won't be me that rings them next time, but I kind of feel like I can't leave them for another two weeks without a conversation.

INT:   
Mm-hmm.

HP04:  
So it it's nice to keep it as the same person. I think, particularly if it and that's generally what we would try and do, but often that initial conversation could be somebody else.

INT:   
Same pass.

HP04:  
But I think if you're following someone up over a long period of time, it's better to be the same person, but that doesn't always work, and as long as I think that the patient knows that that.

But I think that's still fine if it's better, I think that they have that support from somebody than not having anybody.

INT:   
Thank you.

INT:   
And how often should patients living with dementia their medication be reviewed?

HP04:  
Good question. Umm.

HP04:  
OK, what I don't know whether I'd set a time is it depends if the patients getting on with their medicines fine and they don't have any concerns and they don't have any issues and they feel like probably yearly is fine. But obviously, if the patient's not having but then they might not even need a yearly review. If you've managed to, kind of, if you've already had a really in depth conversation with the patient, you've they've had a structure, medication review, you've like reduced all the medications that you feel are the ones that could be described, then they potentially don't even need to be reviewed every year. f you've already had that conversation and whittled them down to the things that are essential if nothing's changed in that person's, so to that person circumstances, and they don't want to change their medicines, then I mean, I guess from and, but it also depends what medicines they're on, because some medications require monitoring.

INT:   
Umm.

HP04:  
Require monitoring and so obviously if they're on something else that will cause monitoring, then we would need to bring them in to monitor that medication.

INT:   
Umm.

HP04:  
So I wouldn't set a specific time frame because it depends on the patient. Depends on what medicines they're on. Depends on. I mean, I guess we kind of generally say yearly as a guide, but that's not really right for everybody because some people might want to be have a conversation more frequently than that.

HP04:  
People might wanna have a conversation if their circumstances change. Some people you might feel like, well, actually I would you down to like 2 medicines.

INT:   
Umm.

INT:   
Yes.

HP04:  
We don't need to talk to you every year, but you come back to us if there's a problem.

INT:   
That's a dependent on those.

HP04:  
Yeah.

INT:   
Patient medications and kind of circumstances as well.

INT:   
Yeah, and sorry, sorry.

HP04:  
And I think, but I mean, but I think I think as a kind of ballpark park figure, it's probably nice to say that actually we should probably think every year and if the as and but if the patient's happy and they don't want it every year, then that doesn't necessarily need to happen. And actually there's no point is reviewing every year. We're not gonna do anything so. Yeah.

INT:   
If they kind of a goal but flexible with within that to the to the patient and medication and circumstances and what are the potential facilitators in integrating shared decision making and relation to deprescribing medication for patients with dementia into your everyday practice, things that might help.

HP04:  
And well, I guess I mean I think just patients knowing that they can ask that question. And I guess and I guess that's also like the patients carers knowing that just because they're on these medications, they don't have to, yeah, they have to be taking those medicines, they can have a discussion about stopping those medicines.

INT:   
Umm.

HP04:  
And I guess that's also probably where the care navigators come in and the and the dementia care navigators in, like, encouraging the patient to feel free to ask those questions if they're, if they're that patients support mechanism and they feel that the patient is struggling or just being open with the patient to say have you thought about your medicines, have you thought having a conversation with somebody and kind of encouraging the patient to take that on or the patient's carer to kind of have that conversation because we we're really bad at reaching out to people because we just don't have time. So I'm more than happy for people to approach us, but it's getting that message out, isn't it?

INT:   
then on the other hand, what are the potential barriers to integrating shared decision making in relations deprescribing my medication in patients with dementia into your everyday practice?

HP04:  
We're having the time to do that and having the yeah like that that kind of shared up like multidisciplinary kind of team like, I mean the more the more I talk about it, the more I think, well, it'd be lovely if we actually met some of these. Can dementia care navigators and ... what had a conversation with them and what they did and told them actually like if you come across a patient on our patch then please refer them in if you feel like they're struggling with their medicines and that or they want to have a conversation about the medicines.

HP04:  
Cause nobody spoken to them about them, then that option is there.

INT:   
So that that that joined up again and the dementia can navigate is knowing he might know they're ...

HP04:  
Yeah.

HP04:  
And I think, and I think the same could be said to be honest for the older person's mental health team, cause we make referrals to them, they just write back to us and say, can you do this? And then we look at what they say and think, well, that's not appropriate for this patient. We do suggesting that it's that kind of thought. Not yeah. Nobody having time to talk to each other and kind of everybody just sit sitting in their own little kind of silos, I guess, and doing what they think is right for the patient. But not having time to have that joint conversation.

INT:   
Right.

HP04:  
And actually often, yeah, I mean often we refer to mental …. persons. Older person's mental health and thing because we don't really know what we wanna how to manage this patient or what is best for this patient now. But then they'll make recommendations, and we might think, well actually is that the best in in the best interest of this patient, I mean, antipsychotics and dementia are prime example, like you often you'll find we'll find the older person. You're a first one to older persons. Mental health. They'll just start them on an antipsychotic and you'll think, well, that's not what I wanted to happen. Then I thought, well, why do we refer him in the 1st place? Because we asked for their support. And I'm yeah. So you I just doesn't have the time to do the whole multidisciplinary team working and have a conversation with the patient and the rest of the rest of the team, which would be the ideal way of dealing with it with most of these circumstances and actually involving the like, yeah, making sure that we've got a dementia care navigator involved in those discussions who might actually say that's fine. I can support this career at home. So you don't need to start the antipsychotics for their behaviour, because we'll do that part of the support.

INT:   
Thank you.

HP04:  
So yeah, that's probably a good example.

INT:   
And can you identify any training or educational needs for you or your colleagues to enable you to safely stop unnecessary medications for someone, dementia or mild cognitive impairment?

HP04:  
Well, I'm not the right person for you to ask. I've started doing some of the trainings. So yeah, I mean, they're definitely is a need for, for training on deprescribing. I mean again, not specific. I haven't specifically done it for dementia patients, but just general kind of deprescribing, and I've been working with the Wessex AHSN to do some kind of action learning sets on polypharmacy. So we know that there's an issue of education for healthcare professionals on deprescribing same people having the confidence to be able to, yeah, to make decisions. I'm when it comes to describing so. So yes, they're definitely does need to be kind of support and training and pace across the board. I think there are, I mean, like I said, I'm there are a few of us as farms that quite happy to do that. But I know that that's I'm probably the minority rather than the majority.

INT:   
is there anything else you want to tell me or anything you wish to add that that's important that you haven't had a chance to say.

HP04:  
No, I think you probably covered everything.

INT:   
No other thoughts or which reflections.

HP04:  
No, no.

HP04:  
We've been, yeah, doing a lot of work on the on polypharmacy and kind of deprescribing in our in our area along like I said with the (name of organisation). So and yeah, it and I think like across (name of locality), I know that like kind of looking at anticholinergic burden is one of our priorities. But again, it's just having the time to do it. We kind of everybody knows that's what we should be doing. But unfortunately, like yeah, having the time to do to do those kind of things just doesn't happen in primary care. Say you and yeah, it's very difficult to try and balance the kind of reactive work with doing proactive work and that's, yeah, we're continually being pushed towards just reacting to what the patients are sending in. But I'm like actually, if we could get back, if we could backtrack and proactively do the proactive work, we wouldn't have so much reactive work. But it's so difficult to get back into that situation.

INT:  
We've come to the end of the interview now, so I'll just bear with me a second and I'll just stop the this transcript for you.