

#### Supplementary 4. Case study 1.

Pam was in her early 50s when she had her second routine screening mammogram. She thought it was the sensible and right thing to do. She was called back for further testing and just thought it was a false alarm so didn't take her husband along with her to the appointment, where she had another mammogram and biopsies. Ten days later she was told that she had invasive ductal carcinoma, cancer that had spread beyond the milk ducts. She asked at the time of the diagnosis, *'do these things ever go away on their own?'* and recalled that her husband, the doctor, and the nurse looked at her *'as if I was nuts'*.

Three days later Pam started Googling to find out more about her diagnosis and *'it felt like an avalanche of information came back about the possibility of overdiagnosis'*. Her husband read some of the research papers with her and confirmed that they were good scientific studies. Pam explained that it was at that point that it became clear to her that she might have been caught unnecessarily by the screening program, and described feeling 'shocked' upon finding out about overdiagnosis.

She continued to research for another month and then went to see a breast cancer surgeon to discuss treatment options; this was an 'uncomfortable' exchange because she challenged the treatment options offered (a lumpectomy and possibly radiotherapy). She asked for a second opinion and saw another surgeon three weeks later, who listened to her concerns but didn't have anything different to offer. *'I did ask her about something like active monitoring, because I knew that was what was offered to men with prostate cancer'*, where overdiagnosis is also an issue. She was told that (at the time) *'we just don't do that'*. Pam 'reluctantly' agreed to a lumpectomy. In preparation, she had an ultrasound where more cancer was detected in the same breast (of the same low grade, both <1cm) after more biopsies and a mammogram. She was told then that a lumpectomy was no longer an option and a mastectomy was recommended.

By this point Pam was exhausted from weighing up all her options (it had been 2 months since her diagnosis). She agreed to have a mastectomy (but refused breast reconstruction) and had the surgery and a sentinel node biopsy soon afterwards. She made a good physical recovery. The result of the biopsy was clear, so no radiotherapy was needed, but this provided little in the way of reassurance, as it *'did nothing to convince me that I actually needed the surgery in the first place...I was left with that uncertainty...(and even years down the track), I still don't know if I actually ever needed that treatment'*. In the years that followed, Pam blamed herself for not paying better attention to information about overdiagnosis that may have been in the media and questioned her decisions. The treatment was not without consequence or burden; it brought on menopause and osteoporosis which limited her activities, still affects her choices about what she wears, and impacted on her travel insurance costs, in addition to the months of emotional turmoil that she endured from the decision making, surgery, drugs, and ongoing questioning about whether it was all in fact necessary. Pam acknowledged the difficulties for the medical profession to communicate overdiagnosis but, *'at the same time...I think people should know'*.

## Supplementary 4. Case study 2.

When Jenny received her first invitation for a screening mammogram she wasn't interested in screening because she had *'heard with cancers that it's not always clear and I don't want to be in that situation'*. She was annoyed that an appointment had been made for her without asking her first, so didn't go. The breast screening service called her to ask why she hadn't gone and to rebook her in. She was cooking dinner at the time and wanted the call to end so agreed to go in, assuming that everything would be fine. She was called back and diagnosed with DCIS and advised that she would need surgery (a quadrantectomy). *'They were telling me I needed surgery for something that might never progress...I was put into that dilemma that I had decided I wanted to avoid'*.

Jenny declined the recommended surgery: *'you're telling me this might never progress you don't know whether it will or not and I'm not having surgery for that'*. She sought a second consultation because she thought that the care team hadn't answered all of her questions. At the next consultation she was told that if she didn't have the surgery she might die, because they were unsure whether she might have some invasive cancer (this was the first time that invasive cancer was mentioned); *'I didn't know what to think or how to digest that information. But it was enough to make me think oh god I might be on the brink of death, I've got two children, I have to do this, have the surgery'*. Jenny had a mastectomy, five 'tiny little cancers' were found, the largest 0.25cm (2.5mm). At the time, she believed that *'they had saved my life as we say'*.

It wasn't until a follow-up appointment 3 years later when she said to her surgeon, *'I know I was reluctant, but I would probably be dead by now'* and her surgeon said, *'probably not'* that she worked out *'that really we're talking on a much longer time scale here for the development of the cancer'*. She was filled with 'rage' that she'd not been told before screening and treatment that some invasive cancers are known not to progress, *'even three years later I had still thought although I'd found out a lot about overdiagnosis by then, I had still thought that in my case because invasive cancer had been found that my life had been saved'*. It *'was a process, a slow process of coming to understand what had happened after the event'*.

On reflection she felt that she had been *'utterly railroaded'* and frightened into having surgery when she wasn't ready and was very upset about not feeling fully informed prior to screening and treatment. *'If I had known then what I know now I would have walked away...They put the wind up me, they frightened me. I didn't have a good understanding of the statistics that were quoted'*. She believed that the screening program leaflet (which did not include information about overdiagnosis) had only told her half of the information that she needed to know, that's what hurt so much. She describes the experience as amongst the most painful experiences of her life and commented that she is *'marked by it forever'*. *'They've given me as much (information) as they're giving, and I haven't got a right to anymore. That's what hurts a lot. The fact that they knew. It's like being the last woman in town to find out your husband is having an affair'*. *'This was a very traumatic experience for me'*.

## Supplementary 4. Case study 3.

Sally was aware that mammograms are not absolutely accurate in terms of what they show and thinks that she knew that mammograms can overdiagnose. Eventually she decided to go and have one, reasoning *'It's only information. You don't actually have to do anything about it'*. Sally was diagnosed with ductal carcinoma in situ. She had not heard of DCIS before but was told *'it's not cancer but you'll probably have a mastectomy'*; which she perceived as a 'ridiculous' recommendation, given that she had been told that she didn't have cancer, and may never have. The breast surgeon told her that DCIS will definitely develop into invasive cancer and could kill her if she didn't have the recommended mastectomy. Sally was *'looking for a conversation'* with her surgeon but left feeling *'utterly patronised...no autonomy...No right to have any decision about anything at all'*.

The surgeon that she went to for a second opinion also only offered mastectomy, but she contacted a breast surgeon that she had come across in the DCIS literature by email and said, *'I really wish I hadn't had that mammogram...do you know anyone...who would be prepared to even have a conversation about treatment that (isn't) so radical?'* Surgeon no.3. also said that he had to advise mastectomy but was willing to compromise with a lumpectomy - which she had (plus another to attend to margins) - and regular monitoring. Sally described the surgeon as *'worried the whole time, that he wasn't giving me the treatment...that he understood to be the gold standard'*. She independently read a lot of research to understand her diagnosis and options. Reflecting on her experience, Sally described it as *'frightening...when the people who did talk to me about DCIS talked about it, they talked about it as inevitably advancing to aggressive cancer. Inevitably'*. And described how *'incredibly difficult'* it was to push back against clinicians, one who asked what 'nonsense' she had been reading because she had decided not to have a mastectomy. The conversations she has with her current surgeon are open and supportive.

Sally felt that if she had gone through with the mastectomy and reconstruction she would be *very, very angry* now, because she's fine. She would have missed out on important career opportunities that have presented in that time, she suspects that she would have stopped working or at least reduced her workload, due to the physical consequences of surgery but also because *'you're turned into someone who can't make any decisions...and it's very hard to imagine how you could simultaneously have that identity and also have an identity of someone who's making decisions all the time in their workplace'*. *...I have done the things that I really wanted to do in my professional and my personal life in a way that I would not have been able to do if, in my view, I'd had a mastectomy and reconstruction'*. Sally hoped that in future all women could be given a clearer account of what a screening mammogram can and cannot do, including the likelihood of getting an ambiguous outcome like DCIS, and for treating teams to consider patient preferences. She supposed that there are hundreds or thousands of women in positions like her who have had a mastectomy and moved on with their lives, *'they don't go through the...I created the angst for myself in a way, by finding out about it'*, but she was aware of other women in her workplace who had undergone mastectomies and now think that they shouldn't have.

#### Supplementary 4. Case study 4.

Maureen went for a routine screening mammography, *'I just went and did it as you do and thought it would be fine'*. She was called back for a full assessment which she described as *'the worst morning of my life'*. She felt that none of the treating team showed any care for *'what was going on from my point of view...they just treated me like an object. I didn't feel like a person at all'*. Imaging showed a tumour in the whole lower quadrant of her breast. Maureen was interested to learn more about her diagnosis and its significance so asked some questions but was told *'oh you don't need to know that...so I didn't know what was going on, nobody was going to explain it and I got very patronising answers'*.

At the time of recall, Maureen did not know about overdiagnosis, and believes that she was *'one of the last in the UK to get the old-style invitation...It only gave the pluses of the screening not the negative'*, rather than the current information that is included with screening invitations, which is *'more balanced about the harms of screening'*. When she didn't receive answers to her questions, she asked, *'what would happen if I just walked away now? and he put his head back and just laughed...and then said, well you would be a fool because you won't know what's wrong with you...No one had used the phrase carcinoma, I didn't know there were different kinds of cancer at this stage, I was naive'*.

Maureen ended up having 14 needle biopsies taken and a vacuum-assisted biopsy, from which she *'bled and bled and bled'*. She was diagnosed with high-grade intraductal carcinoma in 8cm of breast tissue and advised that she would have a mastectomy: *'I think he should've been...not taking the forgone conclusion that I would be having a mastectomy.'* She undertook some research online and discovered the concept of overdiagnosis which was an *'eye opener'*, *'I gradually learned more and more about it and realised that for every life saved there are four overdiagnosis and that it was really serious'*. She learned, *'if you go for screening and have cancer diagnosed you then might have a life expectancy of 15 years whereas if you don't go for screening and then you develop symptoms you might only survive 10 years with cancer but you've already had five good years where you were pre cancer so you're no worse off really.'* On the basis of her own analysis of risk and the advice of some others, *'I ran the risk and kept my breast for another two years'*.

She described being treated as a *'difficult woman'* when she asked for monitoring only but eventually the surgeon accepted her decision and she had a clinical breast examination every six months, but refused any further mammograms. Her friends thought she was *'mad'*, *'they were thinking I was going to drop dead. But I said it's not going to kill me anytime soon'*. Maureen did eventually get a mastectomy three years after her diagnosis, when she developed a symptom of invasive cancer (blood from nipple).

Maureen acknowledged that she *'probably would've got breast cancer eventually. I think if I hadn't gone for screening, I might have lived another three years quite cheerfully not knowing that I had it...not worrying about anything...once I had been to the biopsy, I lived with the fear of cancer coming'*. She explained that her management strategy was to acknowledge that the cancer was there, *'but at the same time to just enjoy life and not get fixated on it'*.

At the time of the interview, it had been 8 years since Maureen's diagnosis, and she was now *'going downhill quite fast'*. She said that she had had 8 good years, and *'I've got no*

*regrets about my reaction I just wish that I hadn't been to the screening in the first place'. She believed that the cancer would have developed more slowly if her breast had not been damaged by the biopsy, 'I think I could've delayed the whole process really had I not been at the mammography screening'. Maureen developed stage 4 (metastatic) cancer and died in 2021.*