

The Fear of Finding Out

Identifying psychological barriers to diagnosis in the UK

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About this report

This report uses literature data, observations and discussions to frame a new approach to understanding the nature and implications of health-system avoidance by individuals who choose to remain ignorant about their health status, due to fear.

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1. Executive Summary

Many people would agree with the aphorism 'knowledge is power', yet some choose to ignore knowledge. In most cases, ignorance by choice relates to something considered unessential. It may alternatively relate to something considered unhelpful. Whilst knowledge of one's health status should be of great personal interest to all, thousands of people every year in the UK choose to avoid health information, even following symptom onset. Some in this group appear to believe that the acquisition of knowledge would in fact be *disempowering*. A significant contingent of this group appears to be in middle age.

In this report we investigate a range of psychological barriers associated with the 'fear of finding out', or FOFO. The term 'fear of finding out' lacks specific definition within health literature, with some studies confining this category to 'worry about what the doctor might find', placing emphasis on outcomes only. However, an individual may fear finding out due to fear of the clinical environment, or due to fears of the investigation processes involved.

We define FOFO as a multifactorial construct comprising many different fear barriers, associated with: (i) the clinical environment, and/or (ii) clinical investigation, and/or (iii) diagnosis. Fears within one or more of these domains may interact with other psychological, environmental, experiential and logistical barriers to help-seeking. To what extent this happens is currently unknown. As this report makes clear, there is a paucity of quantitative data associated with fear barriers to help-seeking. But while there is still much to understand, the literature allows us to make some important, provisional observations.

FOFO: what kinds of fear?

FOFO is a category of fear barriers that incline individuals to remain ignorant about their health status. Listed in Section 4, patient-identified help-seeking barriers include fear of:

- being physically examined
- the hospital environment
- clinical investigations
- treatment
- stigma and/or discrimination
- being pressured to make lifestyle changes
- appearing weak / not in control
- sexual dysfunction post treatment

We cite 16 fear barriers in total, though not all of equal significance and relevance. Some fears will have stronger associations with particular symptoms or potential disease. A smaller number of fear barriers may arise in response to an invitation to disease screening or general health check.

The identification of those at risk

In general, FOFO may be more common among men, but evidence does not all point one way. Clearly, men and women of all ages can experience fear-barriers. However, there is indication that FOFO is a more pressing issue for those in middle age. Firstly, with middle age comes higher risk of stroke, kidney disease, heart disease, type 2 diabetes and dementia (NHS Choices, n.d.). Secondly, recent data indicate that 77% of men and 63% of women in middle age are overweight or obese, and that diabetes rates have doubled amongst this age group in the last 20 years (PHE, 2016). People with unhealthy lifestyles (including heavy drinkers and smokers) have a greater propensity towards help-seeking delay, and fear-based barriers are known to contribute to this behaviour (Dryden et al., 2012). There is also evidence that within specific disease categories, patient delay may be more common amongst the middle-aged compared to older people (Whitaker et al., 2016; Robb et al., 2009).

The linking of culture and gender is another important consideration for fear-based avoidance behaviour. Moreover, various socio-demographic factors may have direct links to both diminished health status and fear-based delay. For example, low educational attainment has been associated

with both poorer health status (OECD, 2006) as well as fear-based delay to help-seeking (Quaife et al., 2015). A possible interrelationship of social factors, lifestyle factors and health status needs to be studied to better understand FOFO as an exacerbator of health inequalities.

How much of a threat is FOFO to public health?

Any form of help-seeking delay is of considerable concern to public health. It has been shown that delay worsens prognosis for mental health, heart attack, stroke, many cancers, arthritis and infectious diseases, among other conditions (Kannan & Veazie, 2014). Though delay appears most strongly associated with failure to recognise the seriousness of symptoms, FOFO appears to be among the most important categories of conscious help-seeking delay. Fear barriers are certainly often cited in the literature, even if rarely quantified.

One US study found 31% of adults claiming to have avoided a doctor visit they had deemed necessary; one third (34%) of this group cited 'fear of a serious illness' as a key barrier (Kannan and Veazie, 2014). Patient response in one UK study indicated that fear barriers to help-seeking for the majority of cancers may cause around one third (32%) of all conscious patient delay (Forbes et al., 2014). We should not however read too much into the 'one third' statistic at this point, and the impact of FOFO will likely depend on suspected disease or condition, these including mental illness, myocardial infarction (heart attack), infectious diseases, diabetes and rheumatoid arthritis.

FOFO is first and foremost a likely danger to the individual's own health status. However, fear barriers may also be dangerous to others. One literature review found that anywhere from 12% to 55% of people who undergo testing for HIV fail to return to learn whether they are infected (Sweeny et al., 2010). This example also shows how fear barriers are not confined to the same point of the patient journey. FOFO may manifest prior to any primary care contact, following GP consultation and prior to hospital-based testing,

or indeed following testing, with the avoidance of test results. In this respect, the influence of FOFO on hospital outpatient non-attendance rates may be an important research area to inform primary care practitioners in their education and support of patients.

In short, evidence already makes clear that fear-barriers represent a major obstacle to disease prevention and early intervention. FOFO is therefore linked to reduced health-related quality of life and, given its association with life-threatening diseases, may lead to, or hasten, premature death.

Going forward

Many of the issues described above speak to the issue of health literacy, which in its broadest definition includes not just knowledge and capacity but the *motivation* to access, understand, appraise and apply health information (WHO, 2013). And this is important because though health literacy is strongly linked to literacy and educational attainment, intelligent, highly literate people can lack motivation (self-discipline and self-efficacy) to make wise, healthy choices.

It has been suggested that while 40% of the UK population are highly motivated to adopt healthy lifestyles, the remaining 60% have a more negative and fatalistic attitude towards their health (Kings Fund, 2012). A comparison of attitudes perhaps, but evidence suggests health promoters will in time need to convey FOFO-dispelling messages to a diverse population.

In the meantime, much work remains to understand the complexities of FOFO and the extent to which it deters public help-seeking. It is our hope that this paper will encourage further debate and research progress in this important area. Reducing fear barriers may well be essential to tackling negative attitudes, promoting timely help-seeking, improving health outcomes and ultimately achieving greater equity of healthcare within the NHS.

2. Introduction

When people develop a serious illness, prompt access to health services can make the difference between full recovery (or the ability to live well with the condition) and permanent disability; in some cases, it can mean the difference between life and death. Early intervention improves the prognosis for a wide range of conditions, including cardiovascular disease (WHO, 2007), breast cancer (Arndt et al. 2002), mental illness (RCPsych, 2010; Perkins et al., 2005) and diabetes (Dunning and Martin, 1998; NICE, 2011). Moreover, late diagnosis has been associated with higher healthcare costs due to longer and more complex treatments, lengthier operations and hospital stays, and increased likelihood of institutionalisation (Kannan and Veazie, 2014).

It has long been recognised that lack of knowledge of the symptoms of common diseases prevents people from accessing healthcare. Other barriers to healthcare have also been studied, including those relating to access difficulties, time priorities and psychological factors. Such research endeavours to understand why some people decide to delay or avoid help-seeking, whether in response to symptoms, or an invitation to disease screening or general health check.

We have used the term ‘fear of finding out’, or FOFO, to describe an important subset of emotional barriers to help-seeking, which may be stronger in some population groups and contributing to health inequalities. FOFO is a term borrowed from popular culture (where it typically describes the fear of prematurely finding out about vital plot twists or sports results) and has been recently adapted to healthcare, for example in a government-sponsored campaign aimed at middle-aged men in Australia (healthdirect.gov, n.d.).

This report seeks to quantify, as much as is possible, the extent of FOFO and its impact upon population health. Our intention is to stimulate both further debate and primary research into fear-barriers to help-seeking, in order to explore how these might be overcome.

2.1 Methodology

To explore help-seeking behaviour and fear barriers associated with ‘fear of finding out’, a rapid literature review was undertaken in Embase, PsychInfo and Medline, with keywords including: anxiety, fear, embarrassment, help seeking, delay, avoidance, attitudes, treatment barriers, usage, uptake. Relevant articles were identified and abstracts compiled. General internet searches were also conducted to identify relevant grey literature, as well as to understand to what extent FOFO, as an acronym, is recognised and defined by healthcare providers or systems around the world.

3. Help-seeking delay: who is at risk, generally?

A significant amount of work has been undertaken to understand the contexts and complexities of help-seeking delay and avoidance behaviour. Researchers have examined the issues by gathering opinion from (potentially) healthy subjects on anticipated barriers, as well as by interviewing illness-affected cohorts recalling actual barriers. Studies have also been conducted to find out who does and does not attend general health checks. Thus before exploring the 'fear of finding out' and associated psychological barriers, we set context by considering some of the broad factors influencing help-seeking behaviour.

Two key perspectives are commonly employed in the analysis of help-seeking behaviour. One considers lifestyle and habits, the other socio-demographics. Together these inform psychographic characteristics – particularly attitudes, values and opinions – that incline people towards, or away from, help-seeking.

3.1 Unhealthy lifestyles

It is well known that unhealthy lifestyle habits are strongly associated with disease and poor health status. A number of lifestyle factors are also important predictors of help-seeking delay and non-attendance, with odds ratios higher for:

- smokers
- heavy drinkers
- those with unhealthy diets
- obese

(Dryden et al., 2012)

In the UK, obesity is the greatest public health concern of the present day (NHS Choices, 2013). With obesity comes increased risk of the leading causes of early death among both men and women, including heart disease and cancer (ONS, 2012). As indicated in Table 1, obesity substantially raises the risk of type 2 diabetes, a condition that itself increases risks of retinopathy, cardiovascular disease and kidney disease. Diabetes rates have doubled amongst 40–60 year-olds in the last 20 years (PHE, 2016).

Table 1. Relative risk factors for obese people of developing disease, by gender

Disease/condition	Risk factor	
	Men	Women
Type 2 diabetes	5.2	12.7
Hypertension	2.6	4.2
Myocardial infarction	1.5	3.2
Cancer of the colon	3.0	2.7
Angina	1.8	1.8
Gall bladder diseases	1.8	1.8
Ovarian cancer	-	1.7
Osteoarthritis	1.9	1.4
Stroke	1.3	1.3

Table: Kings Fund (n.d.). Source: National Audit Office (2001).

Report. Tackling obesity in England (Report by the comptroller and auditor general HC220

Session 2000- 2001: 15 Feb 2001

Those ‘enjoying’ unhealthy lifestyles may well avoid help-seeking out of fear of being pressured into making lifestyle changes. But this is just one consideration, as we later explore. It has been shown that those who purposefully delay are more likely to value health less strongly, have lower self-efficacy,¹ feel less in control of their health and be less likely to believe in the efficacy of screening (Dryden et al., 2012).

3.2 Socio-demographic considerations

Studies have examined various socio-demographic factors in relation to help-seeking delay, typically taking account of the individual’s response to:

- symptoms; or
- general health check; or
- disease screening invitation.

These are very distinct considerations. Nevertheless, evidence suggests stronger help-seeking associations with socio-economic status (where this includes education), gender and marital status, even if behaviour is variable depending on suspected illness.

1. Self-efficacy is belief in one’s ability to succeed or overcome difficulties.

(i) Socio-economic status (SES)

The literature studies of both Dubayova et al. (2010) and Dryden et al. (2012) found that people from low SES groups are more likely to delay or avoid health checks. However, the picture is complicated by a lack of common definition for SES, which variously encompasses income, educational attainment, employment status, social class and occupational training.

For example, Mitchell et al. (2008) found that delayed presentation for colorectal cancer was associated with lower educational attainment, but not socio-economic status, overall. Similarly, Quaife et al. (2015) examined the relationship between SES and cancer, but with SES indexed by education alone. This UK study found more widespread fears about cancer survival and treatment among less-educated groups, while admitting that the presence of additional or alternative SES markers may have produced different results. The study noted a common belief among those with lower educational attainment that cancer treatment is worse than the disease itself, a finding of important relevance to fear-based delay.

Kannan and Veazie (2014) argue that whilst socio-economic characteristics are related to care avoidance, only psychographic characteristics (lifestyles, opinions and attitudes) persist in explaining avoidance when controlling for all traits. However, this does not undermine the claim that people from low SES groups are more likely to avoid care.

SES is indeed an interesting consideration across all strata. Whereas emotional barriers appear more prominent in lower SES groups, practical barriers (e.g. too busy) are more prominent in higher SES groups (Robb et al., 2009).

(ii) Gender

Studies have generally found stronger propensity among women to attend scheduled screenings and seek medical help. According to Dryden et al. (2012), 'studies consistently indicate that males are less likely to engage with health checks or screening and to endorse periodic health examinations than females'.

Yousaf et al. (2015) found men enduring symptoms for longer before seeking medical help (especially with the absence of restrictive physical symptoms), and men reporting higher levels of embarrassment during or in relation to medical appointments. The study highlighted fear-based issues of perceived challenges to (notions of) masculinity, such as resilience and strength, and noted particular help-aversion in areas of mental health, including depression.

Gender studies have not all pointed in the same direction, however. Dubayova et al. (2010) cites instances where women have shown either the same or higher tendencies to delay in seeking help for myocardial infarction (heart attack), while Forbes et al. (2014), in a large single UK study on cancer symptom help-seeking, found no clear presentation delay associated with gender.

(iii) Age

Literature reviews have produced equivocal findings in relation to age and help-seeking. Whereas Dubayova et al. (2010) conclude that older people have a tendency to hesitate in consulting an expert, Dryden et al. (2012) state that attenders at health checks are generally older than non-attenders, while noting that some studies have found no association between age and attendance. Yousof et al. (2015), examining male avoidance behaviour, make the point that younger men might be expected to be less interested in attending regular check-ups than older men, many of whom are retired and typically experience more medical problems.

Variance also exists among studies of specific conditions and disease areas. In a worldwide review, Macleod et al. (2009) reported strong evidence of an association between older age and patient delay for breast cancer, but little age-related risk factor with other common cancers. Persoskie et al. (2014), examining a nationally-representative US-based population, found that cancer worry, but not perceived risk of cancer, predicted a greater likelihood of doctor avoidance in respondents aged 50 and older.

In the UK, Whitaker et al., 2016, found older people aged 60–69 years more likely to seek help on cancer alarm symptoms than those aged 50–59. These findings are supported by Robb et al. (2009), who found those 65+ expressing the lowest anticipated delay in help-seeking. Forbes et al. (2014), also examining cancer, cited no clear differences in frequency of delay by age, although noted a ‘trend suggesting that older people might be less likely to delay’.

In the realm of mental health, older adults have been found to exhibit more favourable intentions to seek help from primary care physicians than younger adults (Mackenzie et al., 2006). The UK’s Adult Psychiatric Morbidity Survey, 2014, found those in midlife (especially aged between 35 and 54) most likely to report receiving appropriate treatment (NHS Digital, 2014), although findings are not necessarily indicative of help-seeking activity as such.

(iv) Marital status

Studies generally concur that an individual’s marital status affects attendance rates, with non-attenders at general health checks more likely to be single (Dryden et al., 2012). In a US study, Kannan and Veazie (2014) found lower odds of help-seeking avoidance among married people where a doctor’s visit was deemed necessary by the individual.

However, findings may not be generalisable to all disease areas in all populations. For example, Kessler et al. (2005), examining US trends, found never-married individuals more likely than married individuals to seek help from mental health professionals. Macleod et al. (2009), looking worldwide, found no association between marital status and delayed presentation for common cancers.

Indeed cultural issues need to be carefully considered. Kroenke et al. (2016) in a breast cancer study of nearly 10,000 patients (in USA and China) noted a more pronounced positive impact of having a spouse among older white women, but that in non-white communities it was the engagement of other relatives which appeared to make the difference. The same study observed that lonely women who have survived breast cancer are 60% more likely to die from a recurrence of the disease than those more socially active.

UK cancer studies appear to show stronger conformity to the general observation cited by Dryden et al. (above). Quaife et al. (2015) found more positive attitudes towards cancer treatment among married and cohabiting couples, while Whitaker et al. (2016) found married and cohabiting people more likely to seek help on cancer alarm symptoms than single people.

(v) Ethnicity

Reviewing service utilisation in western developed countries, Dryden et al., 2012 found that in general, white individuals were more likely to engage with services than individuals from other ethnic backgrounds.

However, Labeit et al. (2013) examining the utilisation of preventative health check-ups in the UK (individual-level repeated cross-sectional data from 1992 to 2008), found that ethnicity did not have a significant influence on any health check-up.

Robb et al. (2009), in a UK population-based cancer survey, found white participants having greater awareness of warning signs than those from other ethnic backgrounds. On the other hand, white participants expressed greater concerns about not wanting to 'waste the doctor's time' in comparison to ethnic minorities (40% and 24%, respectively). In conclusion, the study found lower anticipated (though not demonstrated) delay among ethnic minority groups. Martins et al. (2013) reported evidence of greater delay among ethnic minorities in breast, oesophago-gastric and colorectal cancers, while admitting insufficient evidence overall to confirm or refute ethnic inequalities in diagnostic intervals of cancer. Linking gender and ethnicity, a recent study has found significantly higher belief among Pakistani, Indian and Bangladeshi women that getting cancer is fate, and that the disease is incurable (Vrinten et al., 2016). Cancer fear was indicated as a significant barrier to help seeking in this study.

Help-seeking delay among the UK's ethnic minorities in mental health is also not well understood. Minority ethnic groups are less likely to receive treatment, with black adults having the lowest treatment rate of all (APMS, 2014). It has been suggested that this owes in part to a lack of UK services that take into account specific cultural needs or considerations (MHPF, 2015). Memon et al. (2016) report a variety of barriers to help-seeking in the UK, as expressed by ethnic minorities, including reluctance to discuss psychological distress (among men) and perception of social stigma, both of these being important fear-based considerations.

3.3 Conclusion

A number of behavioural and socio-demographic factors need to be considered in order to predict delayed presentation among the UK population. However, as briefly explored in this chapter, there are many disagreements among studies.

There are nevertheless strong indicators of help-seeking delay among those with unhealthy lifestyles and low educational attainment. This speaks strongly to the issue of health literacy, commonly defined as the degree to which an individual has the capacity to obtain, communicate, process, and understand basic health information and services to make appropriate health decisions (CDC, 2016). But consideration of psychographic characteristics takes us further: an overweight, university-educated single male who drinks heavily is likewise at increased risk of help avoidance behaviour. Arguably, a more helpful definition of health-literacy is one that includes 'motivation' (WHO, 2013).

At the same time, the interrelationship of SES, avoidance behaviour and illness itself needs to be explored. For example, socio-economic factors play a key part in determining higher rates of poor mental health and wellbeing in BME communities, including higher levels of unemployment and poverty, lower educational achievement, and poorer housing compared to the general population (JCPMH, 2014). Thus both illness prevalence *and* help-seeking delay have been linked with low educational attainment.

Causal relationships of help-seeking delay and disease also need to be considered, within and beyond SES. A person who becomes obese is in turn associated with increased likelihood of health check avoidance (Dryden et al. 2012). Conversely, help-seeking avoidance in a subject that otherwise pursues a healthy lifestyle can in turn lead to exacerbation of a health condition due to a missed screening or health check.

Circumstances and causes of delay are therefore variable, multifactorial and complex.

4. FOFO and the framework of barriers to help-seeking

Lacking a recognised literature definition of ‘fear of finding out’, we sought to compile fear-barriers associated with FOFO as a subset of delay and avoidance barriers. Table 2, informed by a rapid literature review, presents a comprehensive (but possibly not exhaustive) range of psychological, experiential, perceptual and situational barriers, each representing a conscious decision to delay or avoid help-seeking.

The list does not therefore include ‘failure to recognise symptoms’, ‘forgetfulness’ or ‘ignorance about the availability of services’. The literature reviewed includes case-controls, cross-sectional studies and systematic reviews. In the main, these investigate:

1. experience of illness-affected populations (patient recall)
2. non-attendance at health checks and screenings
3. general population viewpoints (where theoretical help-seeking scenarios are presented to potentially healthy subjects).

The FOFO category identifies expressed fears, of varying intensity, associated with a desire to remain ignorant about one’s health status. The category itself comprises: (a) fears of the environment in which the finding out takes place; (b) fears of investigative processes; (c) fears of outcomes and implications.

The column citing ‘examples in the literature’ is by no means exhaustive: the number of studies listed against any one barrier is not indicative of cited frequency within the literature. Many examples are in any case literature reviews that draw on multiple references. However, it is important to stress that we do not consider each expressed barrier to be of equal significance or relevance.

It will be seen that FOFO, as defined in this paper, represents around one third of all conscious reasons why individuals may delay help-seeking. The barriers listed in FOFO, and indeed throughout the categories, cover a wide range of health conditions, which at this point we mostly leave undefined to avoid implying exclusive links to specific disease.²

It is worth noting that the various contexts of healthcare avoidance can alternatively be summarised as: (1) entrenched attitudes and behaviours (due to perceptions or experience), (2) a lack of understanding, (3) a lack of time/prioritisation, and (4) access issues.

2. It will be noted that the term ‘white-coat syndrome’ does not appear in Table 2, only for the reason that attributable help-seeking avoidance has been described with specific reference to experience, embarrassment, worry or fear. White coat syndrome may for example be attributable to fear resulting from a negative prior experience of healthcare, or feelings of vulnerability or even shame. Similarly, a perception of ‘being in good health’, whilst a possible barrier, may be informed by a combination of low expectations of becoming seriously ill and the absence of symptom pain.

Table 2. Deliberate delay/avoidance behaviour: barriers to help-seeking

Context	Sub context	Barrier	Examples in literature	
PSYCHOLOGICAL	Fear of finding out	A	1. Fear resulting from negative prior experience of healthcare (from individual/system)	Low et al., 2015
			2. Fear of hospital environment (finding the environment threatening or associated with death)	Clark et al., 2012
		B	3. (Fear of) embarrassment in disclosing symptoms or possible medical investigation (e.g. related to prostate or rectum)	Forbes et al., 2014 Jones et al., 2014 McLachlan et al., 2012
			4. Fear of follow-up investigations	Whitaker et al., 2015a
		B/C	5. Fear of appearing weak / not in control ...of losing a healthy identity ...of appearing unmasculine	Farrimond, 2012 Nymark et al., 2014 Smith et al., 2005
			6. Fear resulting from previous experience of suspected disease (personal, relatives, friends)	Smith et al., 2005 Burgess et al., 2001
		C	7. Fear of detection of abnormality	Jones et al., 2014
			8. Fear of treatment / painful procedures	Jones et al., 2014 McLachlan et al., 2012
			9. Fear of finding out about serious or possibly terminal illness	Hvidberg et al., 2015 Whitaker et al., 2015b
			10. Fear of being pressured to make lifestyle changes	Dryden et al., 2012
			11. Fear of (personal) shame that may accompany a diagnosis ... shame associated with dirt and uncleanness	Green et al., 2010 Nymark et al., 2014 Smith et al., 2005
			12. Fear of being stigmatised by others (as a result of findings)	Jones et al., 2014 Vogel & Wade, 2009
			13. Fear of partner abandonment	Jones et al., 2014
			14. Fear about effect on career (i.e. discrimination)	Gulliver et al., 2010
			15. Fear of loss of sexuality (or sexual dysfunction) post treatment	Smith et al., 2005
			16. Fear of results getting into the wrong hands	Martin et al., 2015
	Other factors	17. Faith that the body will heal	Green et al., 2010	
		18. Fatalism Including those who accept illness as 'God's will'	Kannan & Veazie, 2014 Vart, F. 2010 Cheatham et al., 2007	
		19. Disinclination to express emotions/ concerns about health ...especially to a healthcare stranger	Yousaf et al., 2015 Gulliver et al., 2010	

Table 2. (Continued)

Context	Sub context	Barrier	Examples in literature
PSYCHOLOGICAL	Other factors	20. Not wanting to be perceived as a time-waster (or neurotic)	Whitaker et al., 2015a
		21. Worry that family members may think symptoms are psychosomatic	Smith et al., 2005
		22. Too many recommendations to follow	Emanuel et al., 2015
		23. Not wanting make a fuss	Whitaker et al., 2015
		24. Desire to protect others (friends/family) from involvement	Nymark et al., 2014
		25. Feelings of awkwardness (EG completing an FOBt for bowel cancer)	Vart, F., 2010.
		26. Feelings of vulnerability	McLachlan et al., 2012
		27. Racism	Marlow et al., 2014 Cheatham et al., 2008
		28. Determination to 'soldier on'	Marlow et al., 2014
		29. Feelings of shame about a condition already known to the individual, such as: <ul style="list-style-type: none"> • alcoholism • eating disorders • OCD 	Naughton et al., 2012 Ali et al., 2017 García-Soriano et al., 2014
30. Denial of problem	Naughton et al., 2012 Stack et al., 2012		
EXPERIENCE / KNOWLEDGE		31. No prior family history of condition	Li et al., 2012
		32. Disliking visits to the doctor <ul style="list-style-type: none"> • Dislike or distrust of doctors 	Green et al., 2010 Kannan & Veazie, 2014
		FOFO (various), including: <ul style="list-style-type: none"> • Knowledge about pain within the process of clinical investigation • Negative previous experience 	(see above)
PERCEPTION		33. Preference for self-management (eg, self-medicating, making lifestyle changes)	Low et al., 2015
		34. Low expectations about likelihood of becoming seriously ill (or poor symptom and risk factor knowledge)	Green et al., 2010 Jones et al., 2014
		35. Low expectation of help from the GP	Oberoi et al., 2015
		36. Lack of awareness of the importance of screening	McLachlan et al., 2012 Cheatham et al., 2008
		37. Attributing symptom to a non-threatening condition / misinterpretation of symptoms	Oberoi et al., 2016 Li et al., 2012
		38. Low fear / lack of concern on symptom discovery / unusual symptom location	Low et al., 2015 Li et al., 2012

Table 2. (Continued)

Context	Sub context	Barrier	Examples in literature
PERCEPTION		39. Absence of symptom pain	Jones et al., 2015
		40. Not wanting to burden the healthcare system	Burgess et al., 2015 Clark et al., 2012
		41. Normalising/ignoring symptoms as a process of ageing (e.g. symptoms of rheumatoid arthritis)	Stack et al., 2012
SITUATIONAL CONSTRAINTS		42. Poor access to services	Kelly et al., 2016
		43. Travel distance	Maheswaran et al., 2006
		44. Disability issues	Popplewell et al., 2013
		45. Competing lifestyle priorities	Low et al., 2015
		46. Language barriers	Marlow et al., 2014
		47. Poor communication with healthcare professionals	Yousaf et al., 2015
		48. Not wanting to attend appointment alone (unavailability of a family member or friend to accompany)	Strutton et al., 2016
	49. Fear of partner violence (retaliation) E.g. avoidance of help-seeking following domestic violence; cultural expectations of keeping family affairs private	Lee & Hadeed, 2009 Hien & Ruglass, 2009	

4.1 Associations of fear with help-seeking behaviour

Fear is an emotion associated with fight or flight. In the healthcare sense, fight corresponds to help-seeking (and fighting the illness) and flight to avoidance behaviour. Fight or flight is informed by perceptions of advantages and disadvantages of particular courses of action, and in the case of healthcare, an individual's 'fight or flight' response is typically conscious and deliberate, not impulsive. Thus on discovering symptoms, an overriding fear that non-action will hasten death may reduce delay in information seeking (fight); conversely, an overriding fear of the treatment process may result in information avoidance (flight).

It is however important to understand whether 'intensity of fear', as an experienced emotion, is intrinsically a useful indicator of engagement or non-engagement.

A literature review by Dubayova et al. (2010) suggests not, at least for the most part. The authors create a scale of intensifying emotion: (i) worry, (ii) fear, (iii) anxiety, (iv) panic/death anxiety. Their review considers only one paper in a discussion of 'worry' (in relation to cutaneous melanoma), with no clear impact found on patient delay. At the other end of the scale, intense feelings of 'panic' or 'death anxiety' are solely associated with faster help-seeking. Findings for 'fear' and anxiety' are shown to produce contradictory behaviour, depending on where the fear is focused. For example, Burgess et al., 1998,

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consider fear in relation to symptoms (greater fear resulting in shorter delay), whereas Burgess et al., 2001, consider fear of the consequences of medical intervention (greater fear resulting in longer delay/avoidance).

At the same time, it is true to say that closely perceived emotions of fear can also result in contrasting patient behaviour:

...attenders may present for screening to reduce the fear or perceived danger of a condition, while non-attenders may have used the same rationale to not present, e.g. they...were too frightened of the possible outcome if they did attend (Dryden 2012).

It is therefore necessary to delve deeper into risk-profiles, disease types and specific fears. At the same time, we need to recognise that perceptions of probable delay in population-based surveys do not necessarily match those of follow-up studies with actual non-attenders. Evidence suggests that what healthy people think would deter them going to the doctor may not be the same as what deters them when they actually experience a symptom (Forbes et al., 2014).

The most valuable data thus derives from follow-up studies with affected patients and non-attenders – recording *what actually happened* – and (ideally) should not be mixed with assumptions made by healthy subjects. Unfortunately, ‘real-world’ studies that consider fears as barriers are relatively few in number, often small-scale, and do not always produce clear behavioural data.

4.2 Conditions associated with FOFO

As already indicated, fear barriers to help-seeking have been expressed in relation to a range of diseases, as well as routine screenings and general health checks. Table 3 provides examples, categorised according to threat to life and treatability. The selection is not exhaustive.

Table 3. Examples of FOFO in selected disease areas

Threat level	Treatable, reversible, eradicable?	Disease or condition	Literature examples	Study comments (summarised)
LIFE THREATENING	Untreatable	Huntington's disease	van der Steenstraten et al., 1994	Sixty-one percent [of non-participants] were afraid to hear that they might become affected, and half (47%) feared the associated untoward effects of such a result.
	Treatable but typically non-reversible	HIV	Dowson et al., 2012 Sweeny et al., 2010	...stigma and discrimination associated with a positive diagnosis was an important barrier... (Dowson et al.)
		Dementia	Martin et al., 2015	There were confidentiality concerns that the screen result would be disseminated wider than healthcare professionals...
	Treatable and potentially eradicable/reversible	Various cancers, including prostate cancer, rectal cancer, malignant melanoma, breast cancer	Forbes et al., 2014	Embarrassment and worry about what the doctor might find were strong risk factors for delay.
			Burgess et al., 2001	Despite believing the symptom could be cancer, some women delayed seeing a doctor because they feared the consequences of medical intervention. These fears had often been influenced by past experiences of cancer in relatives or friends.

Table 3. (Continued)

Threat level	Treatable, reversible, eradicable?	Disease or condition	Literature examples	Study comments (summarised)
LIFE THREATENING	Treatable and potentially eradicable/reversible	Alcoholism	Naughton et al., 2012	Shame and stigma was brought up by many participants as a factor which made it harder for them to seek help.
		Myocardial infarction Heart failure	Nymark et al., 2013 Clark et al., 2012	Help-seeking was influenced...by fear of hospitals, which were seen to be threatening or associated with fear and death (Clark et al.)
NOT (DIRECTLY) LIFE THREATENING	Treatable but non-reversible	Rheumatoid arthritis	Stack et al., 2012	...ignoring and denying the presence of symptoms was driven by a fear of symptoms becoming more intense and permanent, and fears of medical treatments.
	Treatable and potentially eradicable/reversible	Obesity-related health problems	Dryden et al., 2012	...they are aware they are unhealthy and do not want to be told off and have to make lifestyle changes...
		Common mental disorders	Zartaloudi and Madianos, 2010	...respondents have concerns about being pressured to do things in therapy they don't want to do.
			Henderson et al., 2013	...factors increasing the likelihood of delay include prejudice and expectation of discrimination...

Studies such as these have provided strong evidence of fear barriers and contributed important learning to the understanding of help-seeking psychology. But what remains poorly understood is the extent to which FOFO deters public engagement with health information, whether as a response to symptoms, screening or health check invitation. We can however highlight some important provisional findings from specific areas of illness.

4.2.1 Cancer studies

Help-seeking behaviour appears to be most extensively researched in relation to cancers. Across all cancers, failure to recognise the seriousness of symptoms is the main patient-mediated reason for the delay of help-seeking (Macleod et al., 2009). In a UK study of nearly 2,000 patients reporting symptoms, Forbes et al. (2014) found that 27% had not recognised their symptoms as serious and that this was associated with a 'doubling in risk of delay'. Overall, 21% had delayed presentation for >3 months.

Researching beyond 'failure to recognise the seriousness of symptoms', Robb et al. (2009) in another UK cancer study investigated 'notional' barriers to help-seeking. The study found that the most widely endorsed barriers to consultation were:

1. difficulty making an appointment (37% men, 45% women)
2. not wanting to 'waste the doctor's time' (36% men, 41% women) and
3. worry about what the doctor might find (34% men, 40% women).

All barriers were endorsed to some extent (hence figures not equalling 100% across the three barriers). While it would be logical to assume that barriers (2) and (3) are mutually exclusive, there may be instances where a fear of finding out combines with logistical difficulties of appointment making to deter presentation. It is interesting that a greater proportion of women endorsed the barrier of 'worry about what the doctor might find'; however, as noted above (Forbes et al., 2014), expression of perceived barriers may not be a robust indicator of actual behaviour in response to symptoms.

Another relevant study comes from the USA, where Kannan and Veazie (2014) found 31% of adults claiming to have avoided a doctor visit they had deemed necessary. Their study, which by nature excluded the categories of 'failure to recognise the seriousness of symptoms' and 'not wanting to waste clinician's time', found one third (34%) of respondents citing 'fear of a serious illness' as a key barrier, with almost equal proportion (33%) citing 'discomfort with a body examination'.

Patient experience

In their UK study, Forbes et al. helpfully summarise reasons for delay and avoidance behaviour (men and women combined) in relation to 60% of cancers. Findings are shown in Table 4.

Table 4. Cancer help-seeking delay and avoidance behaviour (Forbes et al., 2014).

Reason	N/1999	Indication for cancer population (%)
I did not realise the symptom was serious	540	27%
I was worried about wasting the doctor's time	114	5.7%
I was worried about what the doctor might find	75	3.8%
I was too busy to make time to go to the doctor	70	3.5%
It was difficult to make an appointment with the doctor	48	2.4%
I was too embarrassed to go to see the doctor	32	1.6%

The six reasons cited in Table 4 are not further sub-categorised. For example, 'worried about what the doctor might find' is not detailed according to fear of learning about a serious illness, fear of stigma or discrimination following diagnosis, or fear of treatment processes. Moreover, we cannot automatically associate these findings with other conditions, nor should these findings be assumed equally relevant to each specific cancer. Embarrassment may be an emotion more often experienced with issues of the prostate and rectum, rather than melanoma symptoms, for example. The study did not include lung cancer, one of the most common forms of cancer in the UK and a disease strongly associated with smoking.³

The findings are useful as they place aspects of FOFO in general context. In terms of conscious reasons for patient delay, worry about what the doctor might find (i.e. outcomes-related fears) constitutes 22.4% of cited reasons. If we couple this with the barrier of embarrassment (which itself, in the context of avoidance behaviour, can be considered a form of fear – e.g. see Table 2, no.3), all-cause fear barriers amount to 31.8% of all conscious delay in this study.

In terms of impact on the cancer-affected population, the two fear categories combined (3.8% + 1.6%) represent a sizeable number of people given the disease prevalence. In 2014, there were some 356,860 new cases of cancer in the UK (Cancer Research UK, n.d.). Working to data from Forbes et al., approximately 19,000 individuals that year will have delayed help-seeking for cancer symptoms due to primary emotions of fear. This estimation does not include those for whom fear will have been a secondary or tertiary reason for help-seeking avoidance or delay, yet a decisive factor nonetheless.

Forbes et al. (2014) also recorded delay according to 15 different types of cancer. Significant delay (beyond 3 months) was observed among individuals with prostate cancer (47.8%), followed by rectal cancer (36.6%) and malignant melanoma (28.9%); those least likely to delay were women with breast cancer (8%). Understanding the impact of various fear-barriers across specific cancers is much needed research.

Lung cancer

There were around 46,400 new cases of lung cancer in the UK in 2014, with 24,800 (53%) of cases among males (Cancer Research UK, n.d.). For around 80% of people with lung cancer, the disease is inoperable because it is diagnosed too late (Tod et al., 2008). Just 10% of people diagnosed with lung cancer in England and Wales survive their disease for five years or more.

UK literature on lung cancer and help-seeking delay is not extensive. A small study with 22 lung cancer patients found a median of 9 months elapsing between first symptoms and seeing a doctor, with a median of 12 months to the date of diagnosis (Corner et al., 2005). More recently the British Lung Foundation published findings from Cancer Diagnosis in the Acute Setting (CADIAS), which indicated that around 16% of patients delay presentation to a doctor for more than 12 weeks. These patients were older and more likely to report fear of what the doctor might find (BLF, 2015).

The findings of CADIAS indicate that each year in the UK, nearly 7,500 individuals with lung cancer delay presentation to a doctor, with FOFO a clear issue for many in this group.

3. More than eight out of ten cases of lung cancer are associated with smoking. See: <http://www.cancerresearchuk.org/about-cancer/type/lung-cancer/about/lung-cancer-risks-and-causes> [Accessed 20/12/16]

4.2.2 Heart failure

There have been a number of studies examining heart failure and chest pain in relation to help-seeking, although UK studies are in short supply. This is perhaps surprising, since cardiovascular (heart and circulatory) disease causes more than a quarter (26 per cent) of all deaths in the UK each year – nearly 160,000 (BHF, 2016).

One of the most thorough international reviews of related literature comes from Clark et al., 2012, who noted that ‘help-seeking was influenced far less by fear of worsening heart failure than fear of hospitals, which were seen to be threatening or associated with fear and death’. Help seeking barriers were systematically summarised as:

- confusing, ambiguous, fluctuating symptoms
- lack of professional support to interpret presence and significance of fluctuations in symptoms
- avoidance-based coping
- fear of hospitals
- misplaced reluctance to be burdensome

Avoidance-based coping and (misplaced) reluctance to be burdensome are strong themes in Nymark et al. (2014). In this small Swedish study, participants touched on FOFO themes within contexts of ‘being ashamed of oneself’ and ‘fear of losing a healthy identity’; but perhaps of greater significance was the older patient’s sense of ‘belonging to a specific generation or having a trait of character that led them not to seek medical care unnecessarily’. Another strong theme to emerge was feelings of shame, embarrassment and failure for ‘not living a sufficiently healthy life’.

A review by Baxter and Allmark (2013) confirms how cognitive and behavioural actions to manage health threats can delay help seeking, whilst also noting a common theme of failure to attribute symptoms to heart problems. Included in the latter category are women who do not recognise symptoms due to their perception of heart attacks as being a male disease. While it is true that coronary heart disease (CHD) is the leading cause of death in men in the UK, accounting for one in seven deaths, it is the second biggest killer of women,⁴ at one in eleven (BHF, 2016).

Most heart failure patients, men and women, delay seeking help for several days, even following severe physical symptoms (Clark et al., 2012). Exactly how much of this can be ascribed to FOFO is unclear.

4.2.3 Mental health conditions

One in four people in the UK experience a mental health problem in any given year (McManus et al., 2009), and yet approximately two-thirds of people with common mental disorders (CMD) receive no treatment (NHS Digital, 2016). FOFO has specific relevance to mental illness, where the fear of diagnosis is a fear of being labelled, of appearing weak and not in control, and thus also a fear of stigma and discrimination.⁵

4. Dementia and Alzheimer disease is the leading cause of death for women in the UK (ONS, 2014)

5. We acknowledge that significant work has been undertaken in recent years to end stigma and discrimination associated with mental illness. The ‘Time to Change’ campaign is one prominent example (<http://www.time-to-change.org.uk/>).

According to the UK Adult Psychiatric Morbidity Survey 2014 (NHS Digital, 2014), around one in six adults (15.7%) has symptoms of CMD at any one time. Women are more likely than men to be affected: one in five (19.1%) women have CMD symptoms, compared with one in eight men (12.2%). Women were also more likely than men to have severe symptoms of CMD (9.8% vs 6.4%).

Prime reasons for under-recognition of CMD, and above all depression, in primary care include: (i) a low rate of mood problems as the primary presenting complaint; (ii) infrequent specific enquiry from clinicians; and (iii) uncertainty about diagnostic criteria (Meader et al., 2011). If GPs are often struggling to identify depression, it is little wonder that the public are also.

Deliberate help-seeking avoidance in CMD will be relevant to a much smaller proportion of the population, and yet one sizeable in number due to the high prevalence of CMD.

Zartaloudi and Madianos (2010) found a range of fears associated with treatment, confirming the findings of other studies that the fear of treatment suspends help-seeking (e.g. Deane & Chamberlain, 1994; Deane & Todd, 1996). Fears described include:

- fear of embarrassment and change
- fear of different stereotypes related to treatment
- fear related to previous negative experience with mental health services
- fear related to the treatment type.

Though these fears will be relevant to both men and women, they are more likely to be present among men, since it is extensively recorded that men are more likely to delay or avoid CMD help-seeking than women (Mackenzie et al., 2006).

In a study of the role of masculinity in men's help-seeking for depression, Seidler et al. (2016) highlight several useful findings:

- i. Men may find it difficult to recognise and communicate symptoms of depression.
- ii. Men prefer collaborative interventions involving action-oriented problem solving.
- iii. Masculine norms like stoicism conflict with depression, heightening self-stigma.
- iv. Masculine norms may inhibit help-seeking and reinforce maladaptive coping styles.

The authors argue that 'reframing a more fluid masculinity to integrate depression may boost help-seeking'.

Masculinity, stoicism and attempting to remain 'in control' are key discussion points for FOFO. Among other key insights are the correlates between CMD at-risk groups and those who have greater propensity towards help-seeking delay. Men and women with low educational attainment, and also those living alone (single/divorced), have a higher probability of experiencing common mental illness. These same groups also display higher tendency toward help-seeking avoidance behaviour.

Though the APMS 2014 survey revealed that people in the Black / Black British group also had particularly low treatment rates for CMD, it is not clear as to whether this group has a greater tendency towards avoidance behaviour in this context. Reported fear-barriers to help-seeking by ethnic minorities include reluctance to discuss psychological distress, and perception of social stigma (Memon et al., 2016) – barriers that are clearly not unique to this group. What is apparent is that those who are female, white British, or in midlife, are more likely than others to receive treatment (APMS, 2014).

4.3 Conclusion

It can be seen from the above discussion that significant research is still needed even where patient delay and fear barriers are well acknowledged. Data is lacking in this area because (as noted above) studies that focus on either theoretical or real-life perceptions produce results that cannot be easily synthesised. Even studies examining patient experience may themselves use different methodologies – for example in the definition of 'patient delay' – and frame questions differently.

Going forward, it would be of great value to develop an agreed framework by which fear-based delay can be assessed and evaluated, according to specific disease area or general health check. This not only relates to how questions are framed and help-seeking delay measured, but also to the assessment of any interaction of FOFO with other help-seeking barriers. Further, fear barriers need to be considered at different points in the patient journey. FOFO and patient delay is not restricted to the primary care environment, as we now consider.

5. Understanding patient delay as a process

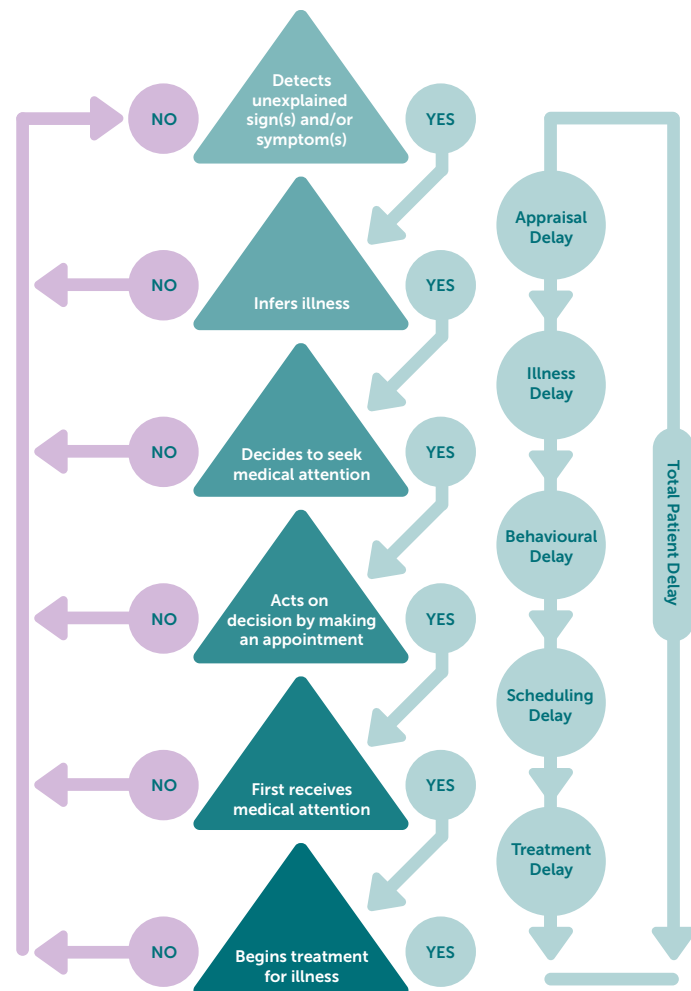
5.1 Patient-delay models

Models of understanding patient delay have been proposed. Among the most familiar is the General Model of Total Patient Delay (Fig. 1), as proposed by Andersen et al. (1995). The Andersen model recognises five stages of delay following the appearance of symptoms: (1) appraisal, (2) illness, (3) behavioural, (4) scheduling, (5) treatment.

Andersen et al. themselves adapted a cancer help-seeking model by Safer et al. (1979) to create a General Model of Total Patient Delay that could be applied to a variety of disorders. In the Andersen model:

1. **Appraisal delay** = time taken by the subject to interpret symptom as an illness
2. **Illness delay** = time elapsing from the point an individual concludes he or she is ill to the decision to seek medical help. (The subject may attempt to self-treat, or ignore, the illness.)
3. **Behavioural delay** = time elapsing between the decision to seek medical attention and actual appointment making. (The subject may choose to postpone appointment making.)
4. **Scheduling delay** = time elapsing between the person making an appointment and first receiving medical attention. (The subject may advertently or inadvertently not attend)
5. **Treatment delay** = time between the first appointment with a healthcare practitioner (HCP) and the commencement of treatment

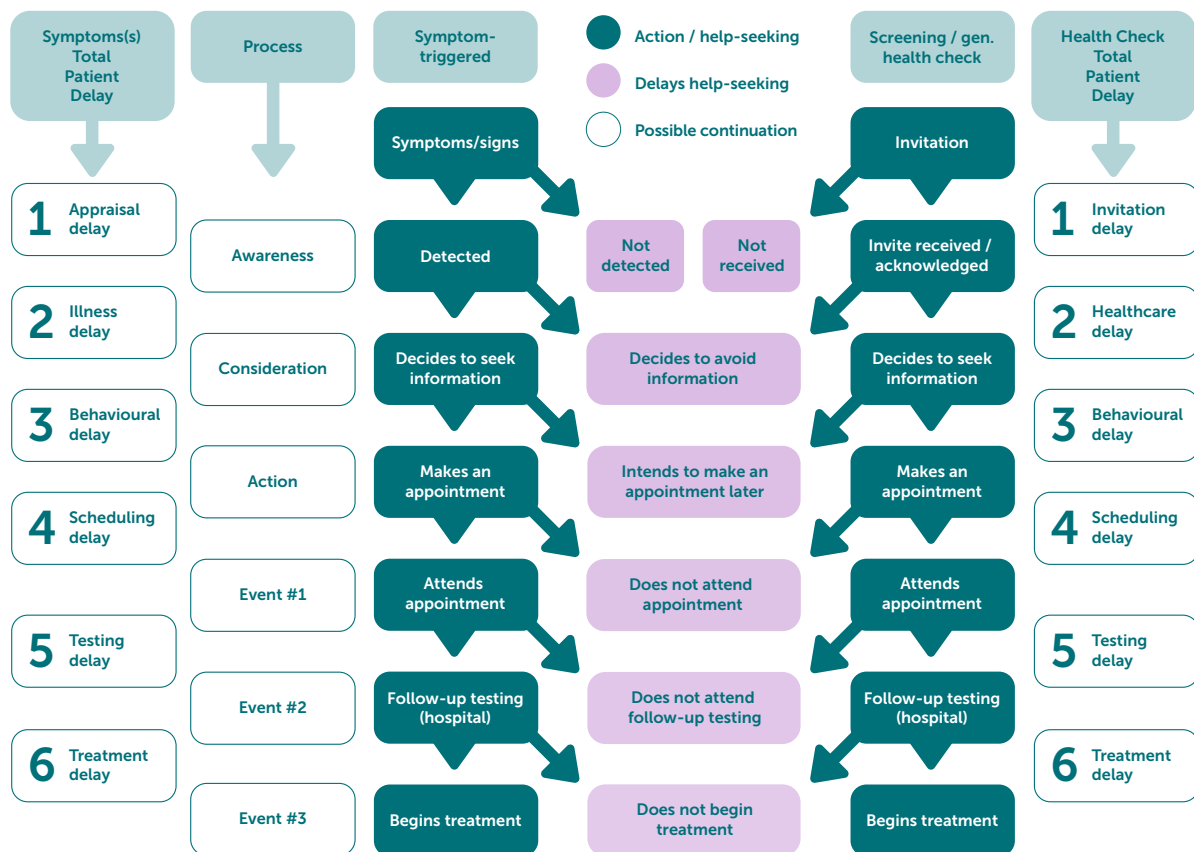
Figure 1. Andersen General Model of Total Patient Delay (1995).



Stages 1 to 4 account for patient-acted delay. Stage 4 also includes services delay (the first available appointment), and stage 5 is largely services delay, associated with the commencement of treatment, although even here the patient can cause delay, both by avoiding specialised hospital tests prior to any actual treatment, or not accepting the earliest available treatment. The diagram emphasises that delay is an inevitable part of the patient journey, regardless of intentional delay or avoidance behaviour.

By redrawing and expanding the Andersen model, we can visualise a process both for delay in response to symptoms, and delay in response to specific screening invitation or general health check (Figure 2).

Figure 2. Expanding the Andersen General Model of Total Patient Delay



This expanded model takes account of delayed intention to seek help, and also recognises the DNA ('did not attend') possibility. And since a great range of diseases cannot be confirmed in general practice, Figure 2 also recognises specific hospital-based testing as an important stage between first HCP consultation and any subsequent treatment.

Adapting Andersen's model to the health check or screening context, the first two stages become:

1. **Invitation delay** = time taken by the subject to receive or acknowledge screening or health check invitation.
2. **Healthcare delay** = time elapsing from actual perception of screening invitation to the decision to seek medical information.

The utility of the patient delay model

Patient delay models are useful in order to identify stages associated with time elapse from symptom onset through to treatment. They can give clarity not only to average lengths of delay according to disease type, but also highlight relative durations of both unavoidable and avoidable delay along the patient journey.

Table 5 provides an illustration, based on data obtained by Andersen et al. (1995) from two studies with women seeking diagnostic evaluations for prevalent cancers: breast or gynaecological tumours.

Table 5. Andersen et al. (1995). Delay associated with breast and gynaecological tumours

Stage	Breast tumour		Gynaecological tumour	
	Days (average delay)	Proportional delay	Days (average delay)	Proportional delay
Appraisal	27	59%	77	79%
Illness	7	15%	10	10%
Behavioural	6	13%	5	5%
Scheduling	6	13%	5	5%
Total	46		97	

The example shows time to first healthcare contact. In an expanded model, as illustrated in Fig 2., categories of ‘tests’ and ‘treatment’ may follow ‘scheduling’.

5.2 Relevance to FOFO

By using patient delay models, researchers can analyse FOFO in context of the patient journey and better understand its health implications, both in specific disease areas and in general screening. FOFO does not necessarily mean help-seeking avoidance until pain becomes unbearable; nor need it imply that an individual will consistently skip health checks and screening. Associated delay may represent one day to many months in the case of symptoms, or one or multiple missed (or delayed) screenings or health checks.

Figure 2 indicates that help-seeking barriers, including several pertaining to FOFO, may not all occur at the same point in the patient journey. A person attending primary care might not realise that presenting symptoms indicate a potentially serious illness, such as cancer. FOFO could in theory manifest after first GP consultation and prior to hospital-based testing – the point where the individual realises their condition may be very serious – or indeed following testing, with the individual purposefully deciding to remain ignorant of test results (Sweeny et al., 2010).

Barriers between primary and secondary care are an important consideration given that nearly one in ten outpatient appointments results in non-attendance in the UK (NHS England, 2016). This is attributable to a wide range of factors, such as being unaware of the appointment or claiming prior cancellation (e.g. Corfield et al., 2008). To what extent FOFO contributes to the DNA rate is unclear, and will likely vary according to disease area. But FOFO is to be expected in this context. For example, studies have found treatment anxiety a contributor to DNA rates for outpatient diabetic retinopathy screening (Strutton et al., 2016). Again, this is a pressing area for further research.

6. Summary and recommendations for further research

It should be remembered that in terms of all-cause reasons for help-seeking delay, failure to recognise the seriousness of symptoms is often the most important, particularly in the context of cancer (Forbes et al., 2014). Improving the public's ability to recognise symptom warning signs is critical to improving outcomes and tackling inequalities in this area.

Public health strategists face a different kind of challenge in addressing conscious avoidance behaviours. In this paper we have given definition to the 'fear of finding out', or FOFO, as a multi-factorial subset of fear barriers within a wider framework of conscious help-seeking delay and avoidance barriers. We argue that FOFO should be considered a more comprehensive psychological category than 'fear of what the doctor might find', which places emphasis on outcomes only.

At the same time, FOFO does not capture all 'fear' about attendance in primary care. It does not, for example, capture 'fear of partner violence', where a person injured through domestic abuse avoids help-seeking due to fear of partner retaliation. FOFO implies that the subject lacks information but wishes to remain ignorant out of fear(s) of:

- (i) the clinical environment, and/or
- (ii) the clinical investigation, and/or
- (iii) the outcomes.

These three spheres of 'fear of finding out' may interact with other psychological, environmental, experiential and logistical barriers to help-seeking. The literature does not provide clarity on how these barriers may interact and, perhaps sometimes only in combination, cause help-seeking delay.

In Section 4, we highlighted 16 expressed fear barriers out of a total of nearly 50 expressed reasons why an individual may decide to delay or avoid help-seeking. The list may not be exhaustive, and it should be acknowledged that each reason does not carry equal relevance. Nevertheless, findings suggest fear barriers broadly associated with FOFO may account for around one third of all conscious reasons why individuals may delay, or attempt to avoid altogether, help-seeking.

Coincidentally, one US study identifying people claiming help-seeking avoidance found one third (34%) of this group citing 'fear of a serious illness' as a key barrier (Kannan and Veazie, 2014). These results resonate with UK data collected by Forbes et al. (2014), which indicate that fear barriers to help-seeking for the majority of cancers may cause around one third (32%) of all conscious patient delay.

FOFO and the identification of those at risk

The lack of literature focus on specific fear barriers to help-seeking makes the identification of at risk groups difficult.

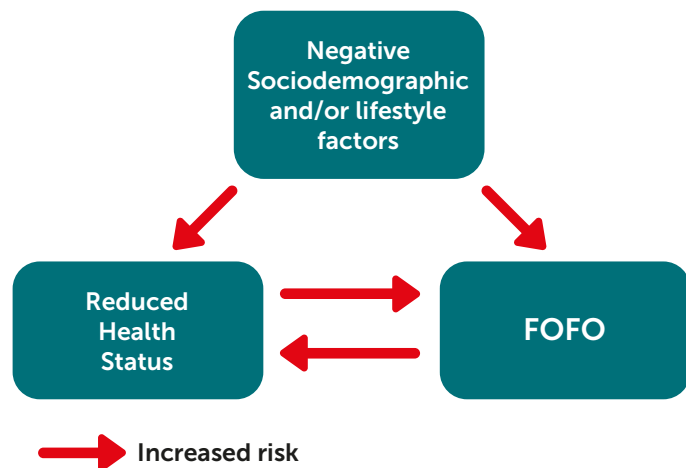
In general, FOFO may be more common among men, but evidence does not all point one way. On the influence of marital status, it has been suggested that women are often the family health managers, encouraging male partners and family members to attend for health checks, thus reducing the risk of delay (Deeks et al., 2009). To what extent fear-barriers are addressed is unclear, as is the general influence of men in encouraging partner help-seeking.

There is however indication that FOFO is a more pressing issue for those in middle age. Firstly, with middle age comes higher risk of stroke, kidney disease, heart disease, type 2 diabetes and dementia (NHS Choices, n.d.). Secondly, Public Health England report that 77% of men and 63% of women in

middle age are overweight or obese, and diabetes rates have doubled amongst this age group in the last 20 years (PHE, 2016). People with unhealthy lifestyles, as discussed in Section 3, have a greater propensity towards help-seeking delay, and fear-based barriers contribute to this behaviour (Dryden et al., 2012). There is also evidence from the UK that patient delay may be more common amongst the middle-aged compared to older people within specific disease categories (e.g. cancer studies of Whitaker et al., 2016; Robb et al., 2009).

FOFO appears linked to low educational attainment and also gender-specific psychology among certain ethnic minorities in the UK. It is also recognised that various socio-demographic factors may have direct links to both diminished health status and help-seeking delay. A possible interrelationship of social factors, lifestyle factors and health status needs to be studied to better understand FOFO as an exacerbator of health inequalities (Figure 3).

Figure 3. A possibility of interrelationship



The identification of at risk groups is of course further informed by disease type, and FOFO will manifest differently within

the contexts of cancer, mental health, type 2 diabetes and infectious diseases, to name a few. Even within the specific field of cancer, the nature of FOFO is likely to be variable depending on cancer site and type, and especially in gender-specific disease, such as breast cancer and prostate cancer.

At the same time, the literature suggests strong similarities of fear across a range of disease areas – for example, fear associated with perceived threats to masculinity. This has important implications for public health messages. The FOFO campaign in Australia, aimed at middle-aged men, is one example of promoting timely help-seeking without specific focus on disease area (healthdirect.gov, n.d.).

Finally, we have seen how FOFO may occur at different stages of the patient journey: prior to GP visit; following referral by GP to hospital consultant; or even following testing, where the individual chooses to avoid test results (Sweeny et al., 2010). The impact of FOFO on hospital outpatient DNA rates is unknown, and yet such knowledge may be useful to guide GPs (and other primary care clinicians) in their support and education of patients.

It is clear that such issues cannot be tackled without addressing the issue of functional health literacy, which in its broadest definition (WHO, 2013):

...is linked to literacy and entails people's knowledge, motivation and competences to access, understand, appraise and apply health information in order to make judgements and take decisions in everyday life concerning health care, disease prevention and health promotion to maintain or improve quality of life during the life course.

'Motivation' is a critical word here. In respect of tackling conscious help-seeking delay, health literacy needs to mean more than 'knowledge' and 'competences'. And while those with low educational attainment are clearly at higher risk of help-seeking delay, we can speculate that health promoters will need to find ways of motivating (and dispelling fears among) a highly diverse public – one not necessarily aligned in socio-economic status.

Research priorities

There is still much work needed to understand to what extent FOFO deters public engagement with health information in the UK. In our view, random population surveys attempting to predict behaviour are of secondary worth compared to studies that capture real-life experience, even if this relies on patient recall. We believe UK-specific research and surveys with affected populations should be the priority. In light of evidence reviewed, we recommend that areas for further research should include:

- Common disease areas:
 - Common cancers / cancers with greatest patient delay
 - cardiovascular disease
 - mental illness
 - diabetes type 2
 - infectious diseases
- The interaction of FOFO with other help-seeking barriers
- The extent to which FOFO contributes to outpatients DNA rates for specific conditions where treatment is perceived as embarrassing, unpleasant or painful
- The influence of health literacy on fear barriers
- The impact of FOFO among ethnic minorities, according to gender
- Gender and marital status
- How technology can play a role in helping people engage with their health
- Appraisal of previous public health campaigns that have attempted to address 'fear of finding out'

It is our hope that this paper will encourage debate and research progress in understanding fear-barriers to help-seeking in the UK. Evidence already supports the belief that a better understanding of fear-barriers associated with FOFO will assist strategies to tackle negative attitudes among the public, raise health literacy, improve health outcomes and encourage greater equity of healthcare within the NHS.

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