

AN EXPLORATION INTO THE FEAR OF FINDING OUT



'CRUSH YOUR FOFO'
DATA ANALYSIS
AUGUST 2018

abbvie

Live·Lab

CONTENTS

Foreword	3
Summary	5
Introduction	7
Participants' profiles	10
Gender	11
Age	12
Understanding what lies behind FOFO	13
Reasons for delaying or avoiding medical advice	14
Responsibility	16
Priorities	19
Source of advice	22
Control	24
Conclusion	27

FOREWORD

The NHS is a treasured institution, held in high regard by millions of patients who depend upon it. As the population ages, and as medical advances make cures and treatments that were once unimaginable, routine, we see increased debate across society about how to ensure the sustainability of the NHS. This is not just about funding – it is about how we, collectively, make best use of our NHS.

It is often assumed that the ‘good patient’ is one who makes as little use of the NHS as possible; stoically putting up with minor ailments and avoiding “bothering the doctor” unless it’s a genuine emergency. This is not always the case. As the NHS focuses more on preventative medicine and earlier intervention, the model of the ‘good patient’ changes to one

who adopts a healthy lifestyle, sees the doctor promptly if they notice what could be the early signs of illness and turns up to routine health checks and screening appointments when invited. Doing so makes it more likely that illnesses will be caught while they can be treated efficiently and effectively, reducing the need for prolonged inpatient stays or late diagnosis, costly treatment and social care.

AbbVie’s Live:Lab project has identified that many of the reasons that people do not go to see the doctor are psychological – people are put off engaging with the healthcare system for a variety of reasons, often stemming from fear. The ramifications of individuals being fearful of seeking medical advice for worrying health concerns, which through Live:Lab, we have identified as the ‘Fear of

Finding Out' are significant, with delayed diagnosis often leading to more costly and complicated treatment putting unnecessary pressure on the NHS.

The Live:Lab project has started to unpack the reasons for those fears and begins to hint at ways that the NHS, and those of us who work closely with it, can begin to counteract them. Some of the reasons were not as expected and I, for one, have been fascinated to understand more about people's fears and what lies behind them. At AbbVie, we are focused on sustainable growth and addressing the world's pressing health challenges, but we recognise that we alone don't hold all the answers. By working collaboratively through projects like Live:Lab, we are able to get ever closer to



finding ways of alleviating pressure on the NHS. The results of this analysis challenge us to use innovation and creativity to find new ways to positively impact people's lives when it comes to preserving their health.

Gwenan White,
Director at AbbVie

SUMMARY

This report has been written by Satalia, on behalf of AbbVie and analyses the open data set captured by the online gamified quiz, 'Crush Your FOFO', which AbbVie launched to the public in February 2018. The quiz was taken by 4,337 participants in the UK.

The report includes the key findings and themes identified in the anonymous data set, including:

Gender

Females recorded higher levels of FOFO in comparison to males

Age

Being in control of health was a lower priority for adults aged between 35 and 60

Impact of FOFO

15% of quiz participants said they would prefer not to know if they had a serious health condition – regardless of gender



Reasons for delaying or avoiding medical advice

Anxiety about being examined was the most common reason for avoiding medical advice, with 25% of participants reporting that they have delayed seeing a doctor for this reason

Responsibility

Over two-thirds of participants (67%) agreed with the statement 'whatever my lifestyle choices, the NHS should always be there for me when I need it'. There seems to be no impact of age and/or gender on the answers to this question



Priorities

There is a positive correlation between FOFO and the tendency to give priority to non-health factors, i.e. the more the participants value something other than their health, the greater their FOFO

Control

There is a negative correlation between FOFO and control, meaning that participants who feel more in control of their health experience less FOFO (and participants who feel less in control of their health experience a greater level of FOFO)



AbbVie is now calling for those who share its ambition to help support a more sustainable NHS to further explore the open data set and this analysis, in order to identify ways of empowering people to overcome barriers that prevent them from engaging with their health.

INTRODUCTION

In January 2017, AbbVie published research in partnership with think tank 2020health, to reveal that the 'Fear of Finding Out' was preventing people from seeking medical advice, even when they have worrying health symptoms. The report, *'The Fear of Finding Out: Identifying psychological barriers to symptom presentation and diagnosis in the UK'*, showed that the Fear of Finding Out makes up nearly a third of all conscious reasons why individuals may be delaying or avoiding visiting their doctor or seeking

medical advice when they may be concerned, or not taking the relevant steps to improve their health. Following the publication of the report, AbbVie convened Live:Lab – a working group of experts from the worlds of data, creativity and healthcare – to come together to tackle the challenge of helping people to overcome the Fear of Finding Out. (Please refer to the Appendix for more information about Live:Lab).

In working to tackle the challenge, the Live:Lab collaborators soon identified



Jeff Brazier and media medic, Dr Zoe Williams helped Live:Lab launch the Crush Your FOFO quiz to the nation

a need for a robust data set to help experts understand what lies behind the 'Fear of Finding Out' – a crucial first step in finding ways to help people overcome it. It was important for the data to be gathered from UK adults in an easily-accessible way with low barriers to entry.

Accordingly, the collaborators designed 'Crush Your FOFO' – a free online quiz which required participants to answer a series of quick-fire questions and participate in gameplay, before being told whether they have the Fear of Finding Out. They were then assigned their very own gremlin representing the severity of their 'FOFO', as well as being signposted to sources of information as a first port of call for health concerns, including NHS Choices.

The questions in the quiz were developed by Dr Carmen Lefevre, Behavioural Scientist from the UCL Centre for Behaviour Change, and were constructed to explore the following overarching hypothesis:

THE 'FEAR OF FINDING OUT' IS INFLUENCED BY PERCEPTIONS OF PERSONAL CONTROL IN THE CONTEXT OF HEALTH

Expanded:

Someone's beliefs around their ability to control their own health, for example through leading a healthy lifestyle, has an impact on their experience of the 'Fear of Finding Out'.

This report covers the key themes and findings identified in analysis of the open-data that was captured by the quiz and serves to highlight areas of further exploration for anyone with an interest in helping people to overcome barriers preventing them from engaging with their health. It also includes thoughts and reactions to the data throughout from Live:Lab collaborators who helped to develop the Crush Your FOFO online quiz.

The anonymous data (which has been made 'open') was analysed by Satalia, a company pushing the boundaries of data science, optimisation and artificial intelligence.

¹ Note: this hypothesis does not state a predicted direction, i.e. it does not state whether perceived control will increase or decrease the 'Fear of Finding Out'. It is agnostic to the direction because theory could support both directions.

**Daniel Hulme,
CEO of Satalia**

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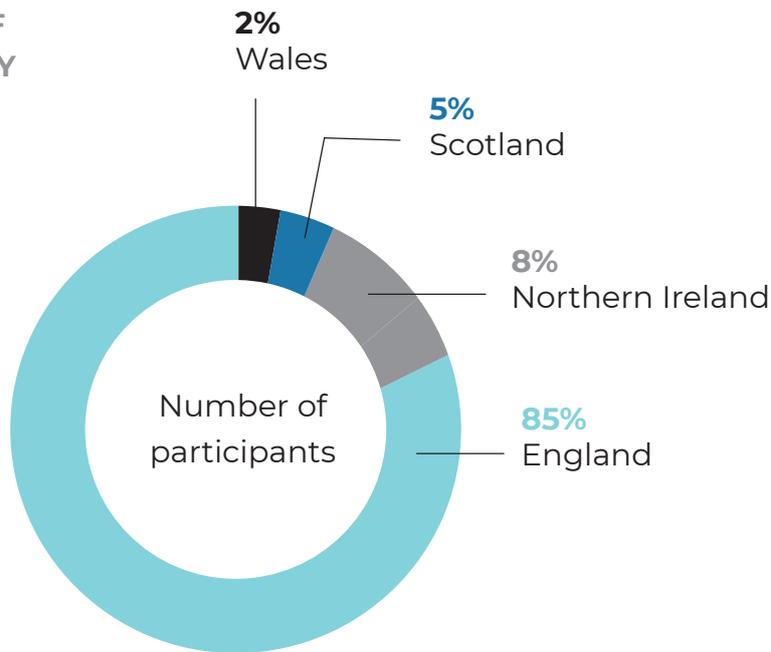
As a data and tech advisor to businesses around the world, I was really keen to help bring this data set to life for AbbVie. It's not always standard practice for companies to make data open but when they do, it becomes so much more valuable. Through Satalia's initial analysis of the open data, we have been able to uncover a number of areas that are ripe for further exploration, for example, people's perceptions of their own responsibility for their health which in turn, opens up conversations around how people engage with the health system. It's hugely rewarding to be part of projects like Live:Lab, which are making data available to further research and understanding of an area.

”

PARTICIPANTS' PROFILES

The quiz was taken by 4,337 participants, the majority of whom were aged between 36 and 61 years and living in England. The analysis also identified which counties have the highest and lowest FOFO scores, as follows:

BREAKDOWN OF PARTICIPANTS BY COUNTRY



- Counties/areas with the highest levels of FOFO included: Shropshire, Nottinghamshire, Northamptonshire, Kent, West Midlands, Devon, Leicestershire, West Sussex, Merseyside, Cheshire

- Counties/areas with the lowest levels of FOFO included: Swansea, South Lanarkshire, London, Durham, Somerset, Oxfordshire, Wiltshire, Berkshire, Yorkshire

There could be scope for further analysis of the counties which display higher/lower levels of FOFO compared to the health status in these areas.

GENDER

Contrary to what might have been expected, females recorded higher levels of FOFO in comparison to males (61% of female participants had FOFO vs. 55% of male participants). It would be interesting to explore whether this can be put down to the fact that females are more engaged with their health and therefore recognise whether they are more susceptible to FOFO than males.



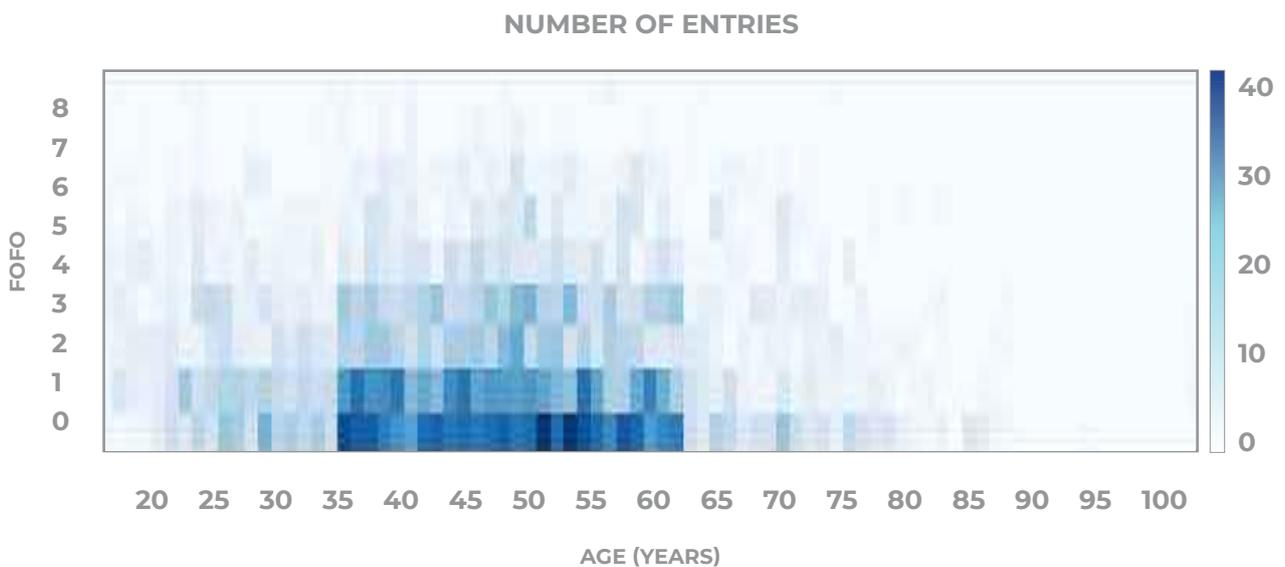
**Alison Hardy,
Headstrong Thinking**

“ I was most struck by the finding that, counter to expectations, women experience greater FOFO than men. This may be linked to a fear of being examined, which the research showed was the single greatest area of concern. There must be more that can be done, particularly through the use of new technologies, to demystify routine examinations, which, though occasionally uncomfortable, should not themselves be a source of fear ”

AGE

Being in control of health was a lower priority for adults aged between 34 and 61, compared to ages either side of that range. When analysing this finding, it's important to remember that this group also makes up the majority of participants responding to the quiz (significantly more participants were aged between 36 and 61), but it is still interesting to consider that FOFO tends to be experienced more in middle-age.

There were significantly fewer participants aged over 78 years, but nonetheless it was interesting to see that digital engagement is not limited to the young; the oldest person to complete the survey was 100 years old.



UNDERSTANDING WHAT LIES BEHIND FOFO

Strikingly, and most directly related to the concept of FOFO, a significant number (634) of participants (15%) said they would prefer not to know if they had a serious health condition – this is the same regardless of gender. The implications of people not wanting to find out whether they have serious health concerns – particularly for diseases like cancer and dementia – pose a significant threat to both the individual and the healthcare system.

The data from the quiz supports the idea that people who experience FOFO tend to prioritise other factors (such as job, family and relationships) over their health; encourage others to seek medical attention more than themselves (i.e. do not take their own advice); and avoid seeing the doctor due to worries about examinations, treatment pathway, and the impact that ill health could have on their family.



Professor Sir Muir Gray

“

We need to clarify the relationship between citizens and the NHS. Publicity is given to the small proportion of citizens who misuse the services offered, much less to the people who underuse the service, often because of the fear of finding out or fear of making unnecessary use of the NHS's scarce resources. To solve or reduce this problem we need to treat citizens like adults, and with the power of the internet, give them their own records and access to the knowledge they need to make the best use of the NHS and, at least as important, look after themselves well. Healthcare is what you do for yourself; the NHS delivers professional health services to support that and the relationship between the two needs to become much clearer.

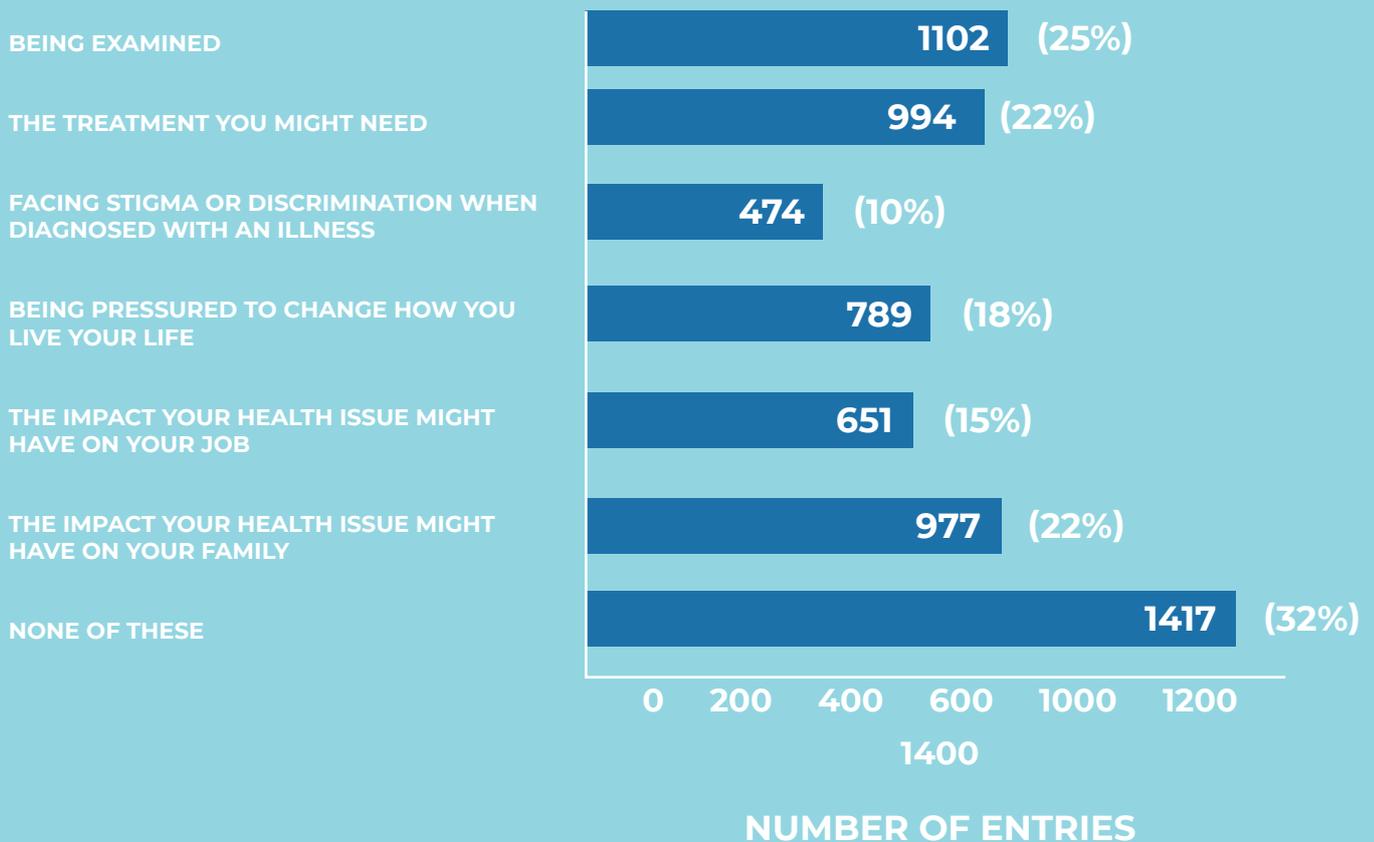
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REASONS FOR DELAYING OR AVOIDING MEDICAL ADVICE

It's interesting to see that anxiety about being examined is the most common reason provided for avoiding medical advice with 25% of participants reporting that they have delayed seeing a doctor due to this concern.

This is closely followed by worry about the treatment that might be needed and the impact a diagnosis may have on family (22%) and friends (22%). A significant proportion of participants (18%) also stated that they have delayed a medical appointment because they were worried they might be pressured to change their lifestyle.

HAVE YOU EVER DELAYED SEEING A DOCTOR BECAUSE YOU WERE WORRIED ABOUT...





RESPONSIBILITY

Personal responsibility has a significant part to play in people engaging with their health. For example, the data indicates that participants who believe their family is the most responsible for their health are more likely to have a Fear of Finding Out.

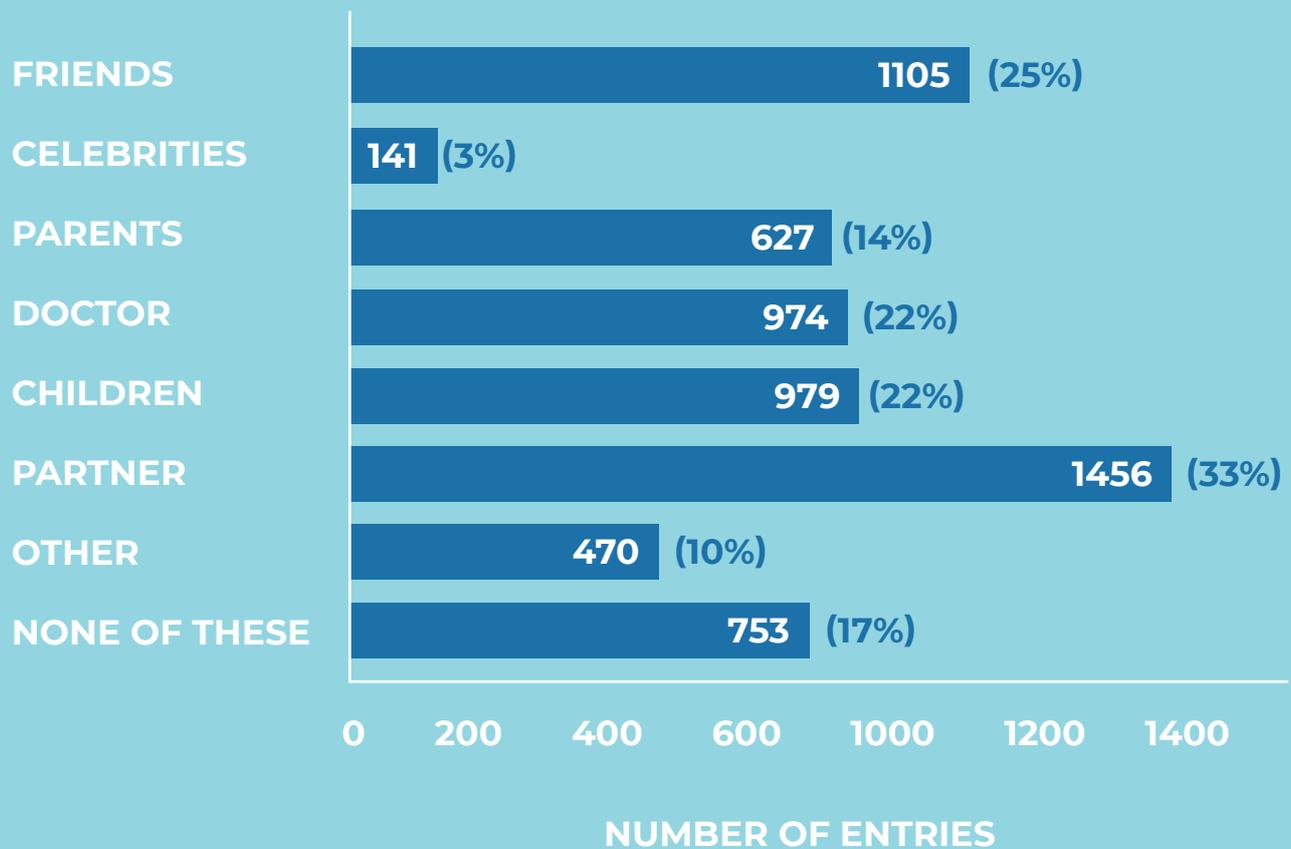
WHO IS MOST RESPONSIBLE FOR YOUR HEALTH?



This therefore suggests that in tackling the nation's FOFO, the promotion of personal responsibility for one's own health would be an important area to explore (be it exercising, keeping appointments, or heeding the GP's advice).

The most likely person to influence participants' health-related decisions is their partner (33%), followed by friends (25%).

ARE THE DECISIONS YOU MAKE AROUND YOUR HEALTH INFLUENCED BY...



The majority of participants expected the NHS to provide a universal service, irrespective of lifestyle; 67% agreed with the statement 'whatever my lifestyle choices, the NHS should always be there for me when I need it'.

There seems to be no impact of age and/or gender on the answers to this question.

**Rachel Power,
CEO of The Patients Association**

“

These results pose interesting questions about patients' attitudes to responsibility and control. Respondents who have a Fear of Finding Out are less likely to report feeling in control of their health, and the responses also imply the existence of a group who feel no responsibility for their own health, but rather expect the NHS to address the consequences of their own lifestyle choices without reserve. We would be very interested to see further research to shed light on these phenomena and unpick the ethical questions they pose.

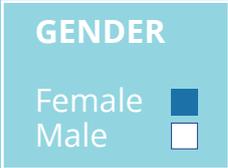
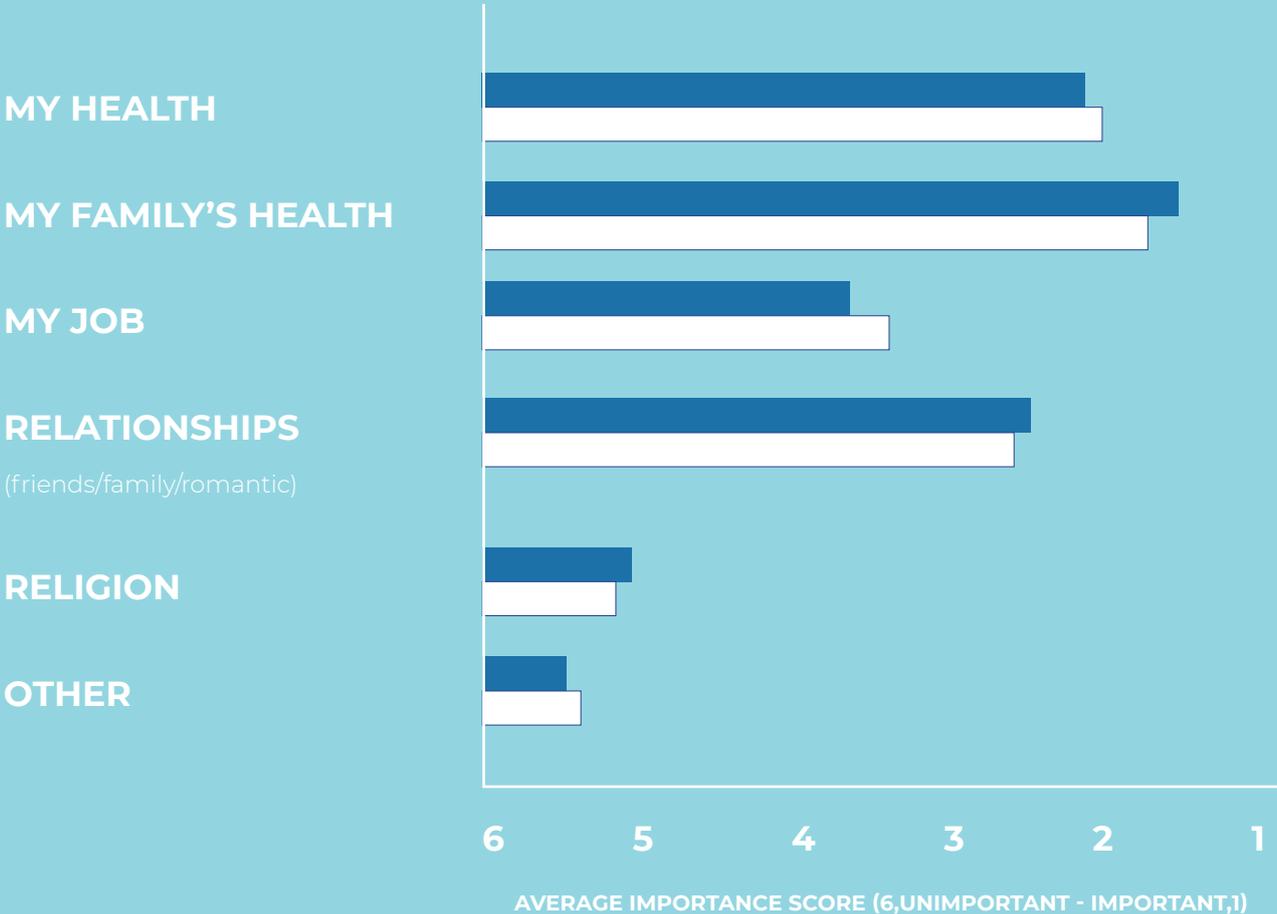
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PRIORITIES

There is a positive correlation between FOFO and the tendency to give priority to non-health factors, i.e. the more the participants value something other than their health, the greater their FOFO (for example, as the importance for a participant's job increases, their FOFO increases as well).

On average, participants prioritise their family's health over their own, a trend that is greater among females who took part in the quiz. Likewise, participants who think that they are better at encouraging others to go to the doctor, than going themselves, tend to have higher FOFO levels – these same people are less likely to prefer to know about a serious health condition they may have.

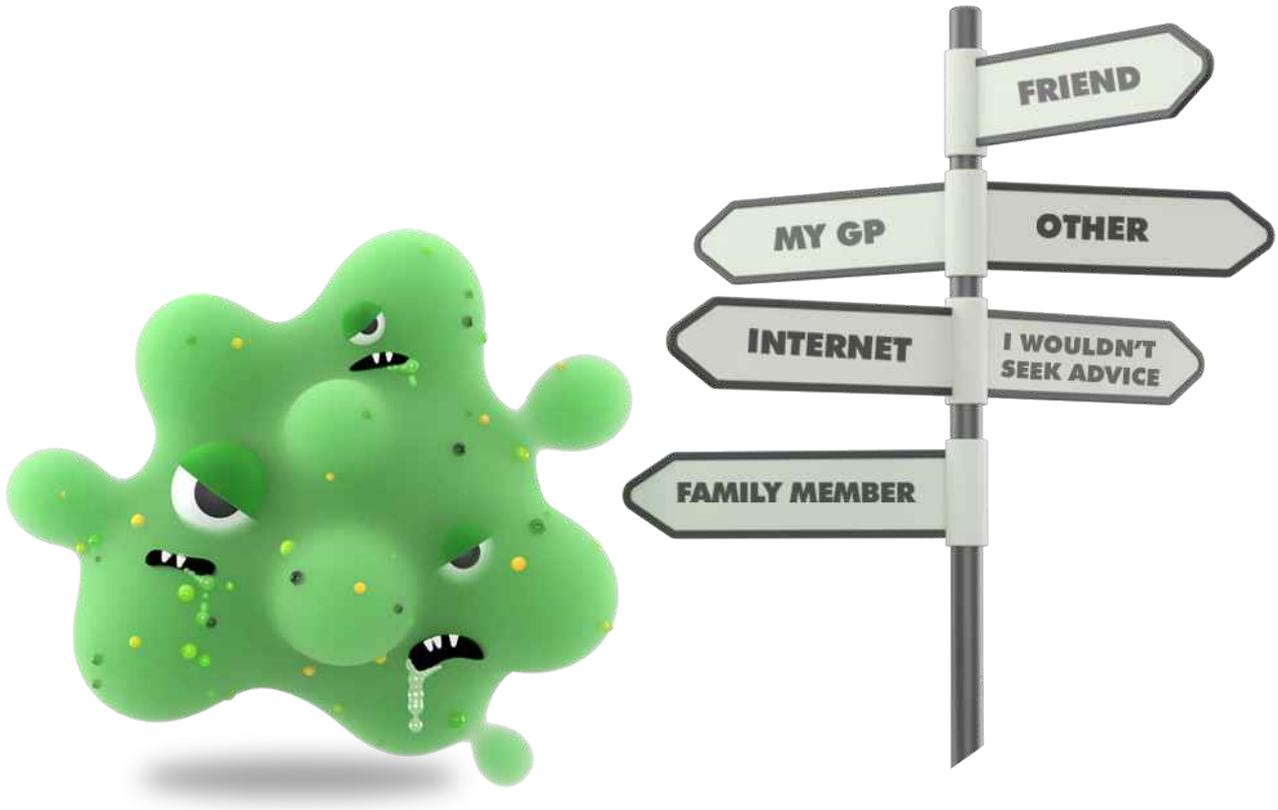
PLEASE PUT THESE IN ORDER OF IMPORTANCE TO YOU



***Alan Milburn,
former Secretary of State for Health***

“ *Having been involved in the Live:Lab project from the outset, when we first established that the ‘Fear of Finding Out’ was affecting the nation’s health, I was particularly interested to see what findings the ‘Crush Your FOFO’ quiz would bring.*

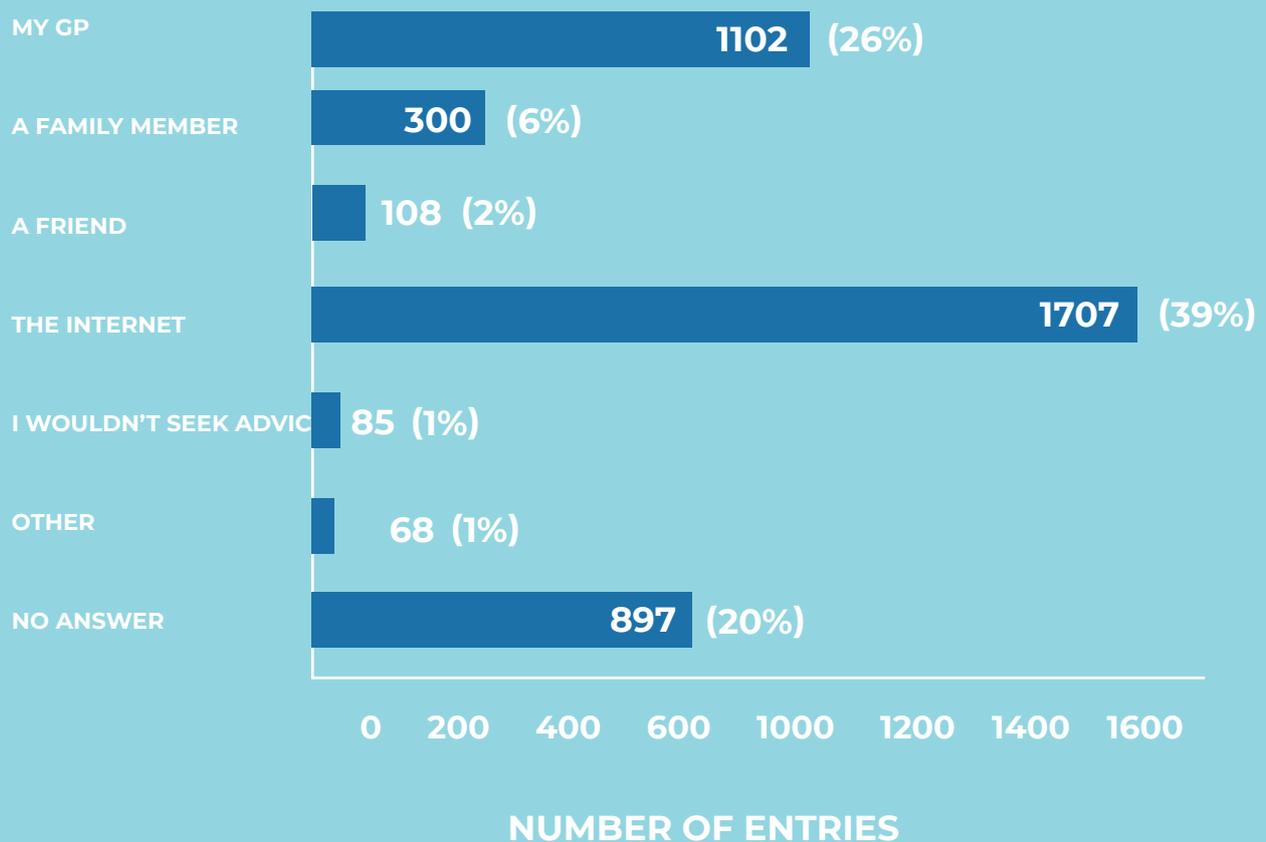
The data from Crush Your FOFO, showed that on average, participants prioritise their family’s health over their own. That trend is greater among women than men. It is something health services should bear in mind when seeking to address issues like FOFO. ”



SOURCE OF ADVICE

The data shows that the internet is by far the most popular first source of medical advice among participants (39%) – this is significantly greater than the number of people who would instead first ask their GP (26%). There is the potential for further analysis of the results to be carried out to explore the most frequent source of advice for people with the highest FOFO.

WHERE WOULD YOU SEEK ADVICE FIRST IF YOU HAD A HEALTH CONCERN?





Jeff Brazier; Live:Lab Chair, Alan Milburn; Dr Zoe Williams; and game designer, Max Scott-Slade take the Crush Your FOFO quiz

CONTROL

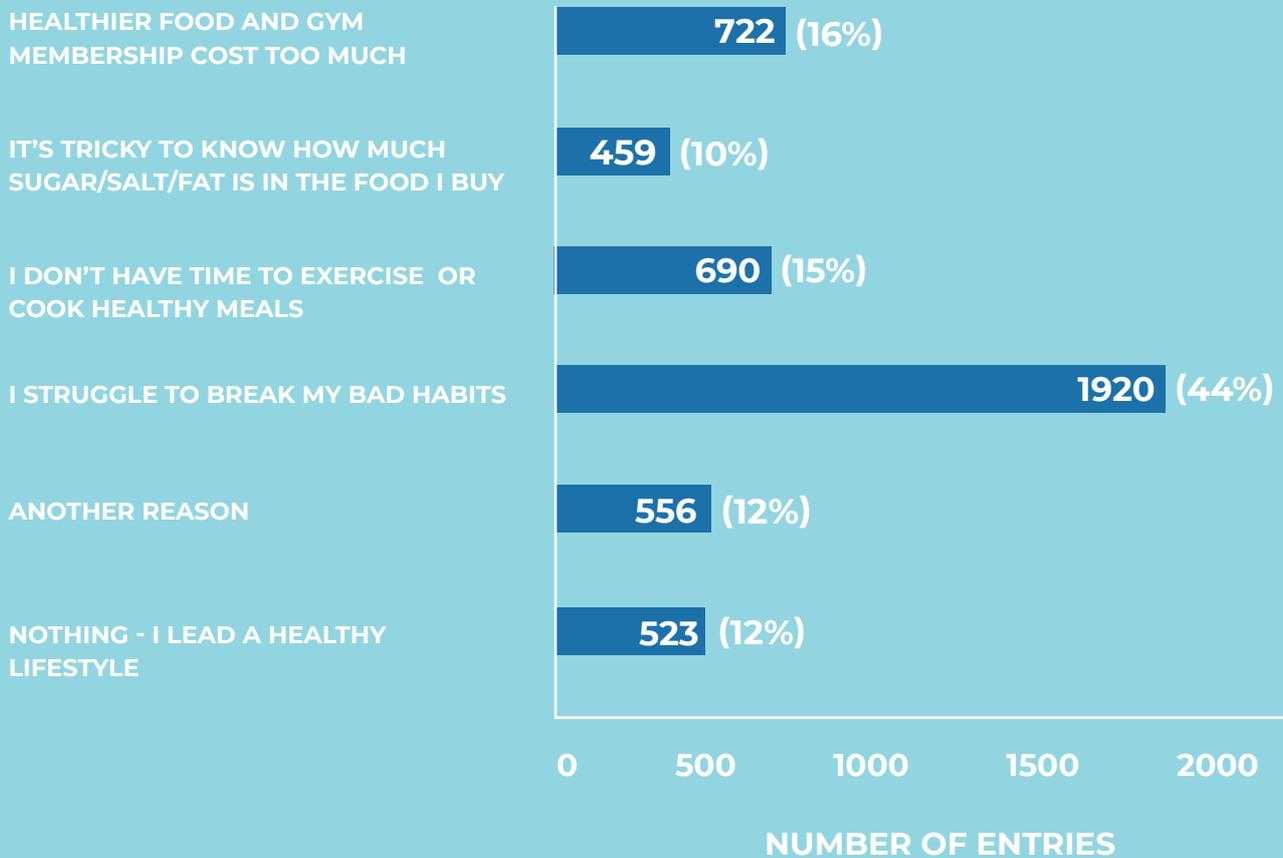
There is a negative correlation between FOFO and control, meaning that participants who feel more in control of their health experience lower levels of FOFO (and participants who feel less in control of their health experience higher levels of FOFO).

Although over half of participants (54%) think that being in control of their health is a priority and understand they cannot necessarily make up for an unhealthy lifestyle later on, there is a substantial portion of participants (17%) who do not think that being in control of their health is a priority. Being in control of

health was a lower priority for middle-aged adults between 35 and 60, compared to ages either side of that range.

The most popular choice, by far, of factors which prevent participants from leading a healthier lifestyle is struggling to break unhealthy habits, with almost half of participants (44%) selecting this response. Other popular reasons include the expense of healthy food and gym memberships (16%), and lack of time due to busy lifestyles (15%). It would be interesting to explore further how individuals in developed countries can best take control of their health.

WHAT STOPS YOU FROM LEADING A HEALTHIER LIFESTYLE?



Putting control back in the hands of the patient is a key focus for innovation developments in the

healthcare sector and this is therefore a particularly rich territory to explore further in future work.

***Dr Angel Chater, Chartered Psychologist and Reader
in Health Psychology and Behaviour Change at the
University of Bedfordshire***

“ *It is interesting to see that the concept of control is a core feature throughout the report. We know as psychologists, that if individuals think that a behaviour, such as seeking medical advice or being more physically active, is within their own control, they are more motivated to invest the effort to perform the behaviour. In contrast, when a person’s ‘locus of control’ is external and they feel their health is beyond their own control (i.e. in the hands of fate or other people such as family or their GP), they are less likely to engage in health-related activities. Findings from this report support these notions.*

This report provides a really useful insight into the barriers of seeking medical advice and changing health behaviours and highlights some core areas to focus on for future interventions when addressing FOFO. ”

CONCLUSION

This project started with a hypothesis that a person's beliefs around their ability to control their own health, for example, through leading a healthy lifestyle, has an impact on their experience of the 'Fear of Finding Out'.

This analysis has validated that hypothesis, finding that people who feel more in control of their health do indeed experience less FOFO.

There were also some surprising findings, such as the greater propensity towards FOFO in women.

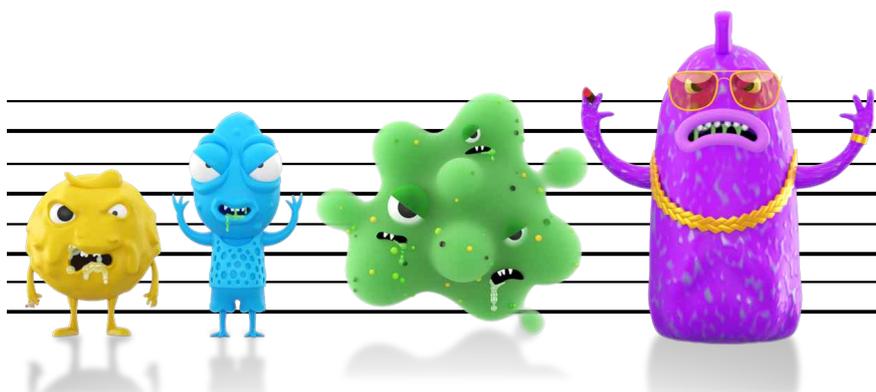
This analysis also showed that the more the people value something other than their health, the greater their FOFO and that, on average, participants prioritise their family's health over their own.

These findings are rich and profound. We could argue that

we now know the ingredients for the antidote to FOFO. Perhaps overcoming the 'Fear of Finding Out' relies on:

- Encouraging people to value their health more;
- Energising people to take fuller control of their health;
- Enabling people to recognise their own role in their health outcomes
- Empowering all of us to take care of those we love and support them to overcome their fears

This is the first step in understanding more about this complex health barrier. This report is intended as a solid starting point for further exploration in what prevents people from engaging with their health, with the ambition of supporting healthcare innovation to help build a more sustainable NHS.



APPENDIX

Questions in the 'Crush Your FOFO' quiz

1) Are you:

- Male
- Female
- Other
- Prefer not to say

2) In which year were you born? (You must be over 18 to continue)

- [free entry of YYYY – only valid responses accepted]

3) Where in the UK do you live?

- England
- Wales
- Scotland
- Northern Ireland

Select your local authority (full list of counties provided later in the Appendix)

4) If you had a serious health condition would you:

- Prefer NOT to know
- Prefer to know

5) Have you ever delayed seeking a doctor because you were worried about:

- Being examined?
- The treatment you might need?
- Facing stigma or discrimination if diagnosed with an illness?
- Being pressured to change how you live your life?
- The impact your health might have on your job?

- The impact your health issue might have on your family?
- None of these

6) How much control do you feel you have over your health these days?

Scale 1 – 5 (1 = no control, 5 = full control)

7) Being in control of my health is a priority for me

- Yes
- No

8) I can make up for an unhealthy lifestyle later in life

- Yes
- No

9) Please put these in order of importance to you (1 – 6)

Note for analysis: It is assumed that 1 = most important, however we must state that this is not explicitly stated within the questionnaire and therefore there is a chance that some participants may have placed their answers in the reverse order than intended.

- My health
- My family's health
- My job
- Relationships (friends/family/romantic)
- Religion or spirituality
- Other

10) Are you better at encouraging others to go to the doctor or yourself?

- Yes
- No

11) Where would you seek advice first if you had a health concern?

- My GP
- Family member
- Friend
- Internet
- Other
- I wouldn't seek advice

12) Who is most responsible for your health? (pick one)

- My doctor
- Me
- My family
- None of these

13) Whatever my lifestyle choices, the NHS should always be there for me when I need it.

- Yes
- No

14) What stops you from leading a healthier lifestyle?

- Healthy food and gym membership cost too much
- It's tricky to know how much sugar/salt/fat is in the food I buy
- I don't have time to exercise or cook healthy meals
- I struggle to break my bad habits
- Another reason
- Nothing – I lead a healthy lifestyle

15) Are the decisions you make around your health influenced by... (select all that apply)

Note for analysis: 'Other' and 'none of these' could have been selected for an option which is not on this list (e.g. uncle) which impacts the outcome

- Friends
- Celebrities
- Parents
- Doctor
- Children
- Partner
- Other
- None of these

16) Have your parents or grandparents ever put off seeing the doctor when they had worrying health symptoms?

- Yes
- No
- Don't know

Full list of counties provided for participants to select

England (County)

- Bedfordshire
- Berkshire
- Bristol
- Buckinghamshire
- Cambridgeshire
- Cheshire
- Cornwall and Isles of Scilly
- Cumbria
- Derbyshire
- Devon
- Dorset
- Durham
- East Riding of Yorkshire
- East Sussex
- Essex
- Gloucestershire
- London (Greater London)
- London (City of London)
- Greater Manchester
- Hampshire
- Herefordshire
- Hertfordshire
- Isle of Wight
- Kent
- Lancashire
- Leicestershire
- Lincolnshire
- Merseyside
- Norfolk
- North Yorkshire
- Northamptonshire
- Northumberland
- Nottinghamshire
- Oxfordshire
- Rutland
- Shropshire
- Somerset
- South Yorkshire

- Staffordshire
- Suffolk
- Surrey
- Tyne and Wear
- Warwickshire
- West Midlands
- West Sussex
- West Yorkshire
- Wiltshire
- Worcestershire

Northern Ireland (District)

- Antrim
- Ards
- Armagh
- Ballymena
- Ballymoney
- Banbridge
- Belfast
- Carrickfergus
- Castlereagh
- Coleraine
- Cookstown
- Craigavon
- Derry
- Down
- Dungannon
- Fermanagh
- Larne
- Lisburn
- Limavady
- Magherafelt
- Moyle
- Newry and Mourne
- Newtownabbey
- North Down
- Omag
- Strabane

Scotland (Council Area)

- Aberdeen City
- Aberdeenshire
- Angus
- Argyll and Bute
- Clackmannanshire
- Dumfries and Galloway
- Dundee City
- East Ayrshire
- East Dunbartonshire
- East Lothian
- East Renfrewshire
- City of Edinburgh
- Falkirk
- Fife
- Glasgow City
- Highland
- Inverclyde
- Midlothian
- Moray
- Na h-Eileanan Siar
- North Ayrshire
- North Lanarkshire
- Perth and Kinross
- Renfrewshire
- Scottish Borders
- South Ayrshire
- South Lanarkshire
- Stirling
- West Dunbartonshire
- West Lothian

Wales (Unitary Authority)

- Blaenau Gwent
- Bridgend
- Caerphilly
- Cardiff
- Carmarthenshire
- Ceredigion
- Conwy
- Denbighshire
- Flintshire
- Gwynedd
- Isle of Anglesey
- Merthyr Tydfil
- Monmouthshire
- Neath Port Talbot
- Newport
- Pembrokeshire
- Powys
- Rhondda Cynon Taff
- Swansea
- Torfaen
- Vale of Glamorgan
- Wrexham

About AbbVie

AbbVie is a global, research-driven biopharmaceutical company committed to developing innovative advanced therapies for some of the world's most complex and critical conditions. The company's mission is to use its expertise, dedicated people and unique approach to innovation to markedly improve treatments across four primary therapeutic areas: immunology, oncology, virology and neuroscience. In more than 75 countries, AbbVie employees are working every day to advance health solutions for people around the world. For more information about AbbVie, please visit us at <http://www.abbvie.co.uk>. Follow us on twitter: [@abbvieuk](https://twitter.com/abbvieuk).

About Live:Lab

AbbVie has launched Live:Lab with the ambitious goal of improving the health of the nation. Through Live:Lab, AbbVie wants to better engage and empower adults, aged between 40 and 60 years old, to take control of their own wellbeing.

The full list of Live:Lab™ collaborators:

- Rt Hon Alan Milburn – former Secretary of State for Health
- The Patients Association - one of the oldest independent charities in the UK, dedicated to ensuring that the opinions of patients are gathered on a wide variety of health and social care issues
- Simon Bullmore, Open Data Institute – a non-profit company with a mission to inspire people to innovate with data
- Julia Manning, Chief Executive, 2020health – an independent, social enterprise think tank whose mission is to 'make health personal'
- Aardman – world leading and multi-award winning British studio which produces series, advertising, interactive entertainment, attractions and feature films; like Wallace & Gromit and Shaun the Sheep

- Glitchers – a company creating innovative gaming products including Sea Hero Quest, an award-winning mobile and virtual reality quiz which collects spatial navigation data to inform dementia research
- Professor Sir Muir Gray – founder of the National Library for Health and the first person to hold the post of Chief Knowledge Officer of the NHS
- Dr Zoe Williams – media medic, GP and clinical champion for the RCGP’s clinical priority ‘Physical Activity and Lifestyle’
- Dr Carmen Lefevre – research associate and research lead at the UCL Centre for Behaviour Change
- Alison Hardy – health behaviour change expert and founder of Headstrong Thinking
- Fundamental VR – medical VR simulation specialist that delivers virtual reality haptic ‘flight simulators’ for surgery
- Dr Angel Chater – chartered psychologist, and a reader in Health Psychology and Behaviour Change at the University of Bedfordshire
- Chrissie Wellington OBE – Global Head of Health & Wellbeing, Parkrun, and British triathlete
- Daniel Hulme, CEO of Satalia – a company pushing the boundaries of data science, optimisation and artificial intelligence to solve the most difficult problems in industry
- The Patients Association – an advocacy group operating in the UK that aims to improve patients’ experience of healthcare. Established in 1963, it is one of the oldest independent charities in the UK and became a registered charity in 1991

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