

RADICAL LISTENING PROJECT On WOMEN'S HEALTH

**Prepared by MCCP for the
Women's Health Taskforce and
the Department of Health**

AUGUST 2021



PRESENTATION AGENDA

Background and structure

- Objectives of the radical listening national workshops
- Format and structure of the national workshops
- Sample overview – women who participated
- Themes, issues and insights from phase 1 & phase 2 for validation

Summary of analysis

- The healthcare context
- The healthcare context for women
- How women currently feel in respect to healthcare
- Women's needs from the healthcare system
- Ideas generated by women to meet their needs

Priority issues & solutions x lifestage

- Universal priority issues
- 20 – 25 year olds
- 26 – 36 year olds
- 36 – 46 year old
- 46 – 60 year olds
- 60+ year olds
- Carers





BACKGROUND AND STRUCTURE

OBJECTIVES OF RADICAL LISTENING

1. Identify the themes, issues and **priorities** for women
2. **Validate and build** on insights identified in the 3 workstreams; 1. Social Media Listening, 2. Qualitative Research and 3. National Workshops
3. **Engage the women of Ireland** with the work of the Women's Health Taskforce.
4. Allow members of the Women's Health Taskforce to participate in the workshops as **active listeners**.



SAMPLE OVERVIEW – WOMEN WHO PARTICIPATED

PHASE 1 – SOCIAL MEDIA LISTENING

- Tweets, discussions in publicly available forums and comments on new sites in Ireland between 22nd July 2019 and 21st July 2020.

PHASE 2 – ONE-TO-ONE DISCUSSIONS

Research Sample	
Total Sample	48
Ethnically Irish	42
Migrants /Marginalised / Non-Irish / ethnic group	6
Lower Social Grade (C2D)	26
Higher Social Grade (BC1)	22
Rural	11
Urban or Urban Settings (Large towns)	37
18 - 24	4
25 - 36	9
37 - 45	9
46 - 55	9
56 - 64	7
65+ (Cut off point in age = 80)	4

PHASE 3 – NATIONAL WORKSHOPS

Research Sample	
Total Sample	180
Lower Social Grade (C2D)	90
Higher Social Grade (BC1)	90
Rural	80
Urban or Urban Settings (Large towns)	100
• 20 – 25 year olds	30
• 26 – 36 year olds	30
• 36 – 46 year old	40
• 46 – 60 year olds	40
• 60+ year olds	30
• Carers	10

Sample broadly reflective of the general population of women in Ireland. Participants were not recruited on the basis of any particular medical history or any particular experiences with healthcare. The only criteria for participation was to be female.

THEMES, ISSUES AND INSIGHTS FROM PHASE 1 & PHASE 2 FOR VALIDATION

PRIORITY THEMES AND ISSUES IDENTIFIED THROUGH SOCIAL MEDIA LISTENING (PHASE 1)

WELL-BEING – PROACTIVELY TAKING CONTROL OF HEALTH

MENTAL HEALTH – HOW TO PROTECT IT, GAPS IN SERVICES

CHRONIC ILLNESS – HEART HEALTH AND CANCER

REPRODUCTIVE HEALTH – CHALLENGES AND FERTILITY CARE

MATERNAL HEALTH – PRE AND POST NATAL CARE OF THE MOTHER

ACCESS, WAITING LISTS AND GAPS IN SERVICES

AWARENESS, EDUCATION & PROVISION OF SERVICES FOR SPECIFIC WOMEN'S HEALTH ISSUES I.E. ENDOMETRIOSIS

CERVICALCHECK - RESOLVING ONGOING ISSUES AND REBUILDING TRUST

FAILURE IN EDUCATION & A LACK OF AVAILABILITY OF ACCURATE AND RELEVANT INFORMATION FROM A TRUSTED SOURCE

GAPS IN THE PROVISION OF CARE FOR THE WOMEN IN RELATION TO TERMINATION OF PREGNANCY

COVID-19 AND THE IMPACT IT HAS HAD ON WOMEN; INCREASED WORKLOAD IN THE HOME, BURDEN OF RESPONSIBILITY

ABUSE & TRAUMA EXPERIENCED BY WOMEN

FACTORS THAT SHAPE WOMEN EXPERIENCES IN HEALTHCARE IDENTIFIED THROUGH LISTENING TO WOMEN'S STORIES (PHASE 2)

AREAS WHERE WOMEN HAVE HAD POSITIVE EXPERIENCES

FACTORS SHAPING NEGATIVE EXPERIENCES



MATERNITY CARE

LIMITED INFORMATION & CONVERSATION

GP SERVICES

NOT TREATED AS INDIVIDUALS

ACUTE CARE

CARRYING THE GREATER BURDEN

SCREENING SERVICES

AN OUT OF TOUCH SYSTEM

Insights from Phase 1 and Phase 2 provided the stimulus for discussion in Phase 3 and therefore this presentation reflects a validation and deepening of insight captured across each phase.

FORMAT AND STRUCTURE OF THE NATIONAL WORKSHOPS

1

Participants are recruited through a professional market research recruitment agency.

As part of invitation to take part each participant receives a letter from Chief Nursing Officer, Rachel Kenna. This letter outlines the importance of the day and their role within it.



2

Workshops, originally intended to take place face-to-face in regional locations across the country, took place on Zoom.

Participants could log in via phones, tablets, desktops or laptops.



3

Each workshop follows the same format and was structured to enable a formal introduction from CNO, Rachel Kenna, and a brief share of learnings to stimulate conversation. Crucially, the workshops **ENABLED 1HR OF STRUCTURED DISCUSSION AND INPUT WITH PARTICIPANTS – SHARE EXPERIENCES, CO-CREATE SOLUTIONS**

Workshop Flow

Welcome & introduction from Ireland's Chief Nursing Office – Rachel Kenna



Presentation from MCCP on findings from workstreams 1 and 2 of the project

Virtual breakout groups – 10 women per group, up to 3 members of the Women's Health Taskforce actively listening



Close – Women's Health Taskforce closing remarks



Key learnings, observations and implications for the Women's Health Taskforce



MCCP



EXECUTIVE SUMMARY



THE HEALTHCARE CONTEXT

MACRO ISSUES, NOT SPECIFIC TO WOMEN'S HEALTH, THAT ARE KEY TO BUILDING TRUST AND CONFIDENCE





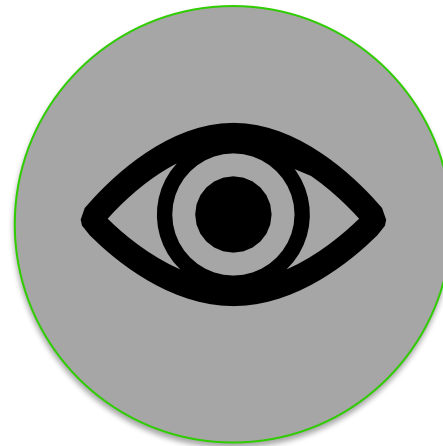
THE HEALTHCARE CONTEXT FOR WOMEN

CONTINUOUSLY NAVIGATING A NEW REALITY, RESPONSIBLE FOR THE CARE OF MANY, EXPECTATIONS TO BE ABLE TO COPE ALWAYS

CONTINUOUSLY FACING A NEW HEALTH JOURNEY AT EACH LIFESTAGE



VIEW THE SYSTEM THROUGH THE LENS OF OTHERS & FEEL RESPONSIBLE FOR THE CARE OF OTHERS



AN EXPECTATION TO KNOW, UNDERSTAND AND BE ABLE TO COPE





HOW WOMEN FEEL CURRENTLY IN RESPECT TO HEALTHCARE

FOR MANY EXPERIENCES WITH HEALTHCARE ARE POSITIVE

FACTORS THAT SHAPE POSITIVE EXPERIENCES FOR WOMEN

MATERNITY
CARE

LISTENING AND EMPATHY, RIGHT SERVICES, AFTERCARE, ENGAGEMENT
WITH THE MOTHER

GP
SERVICES

DIALOGUE, PROACTIVITY, OPEN AND TRUSTED RELATIONSHIP WITH GP

ACUTE
CARE

EFFECTIVE COMMUNICATION, RIGHT SERVICES, AFTERCARE, POSITIVE
OUTCOMES, EMPATHY

SCREENING
SERVICES

ACCESS TO SERVICES, PROACTIVE, TAILORED FEMALE CENTRIC SERVICES

WOMEN FEEL THE HEALTHCARE SYSTEM IS UNDERSERVING THEIR NEEDS

WAYS IN WHICH WOMEN BELIEVE THEIR NEEDS ARE BEING UNDERDELIVERED

LIMITED INFORMATION & CONVERSATION

FEELING UNSUPPORTED, NOT KNOWING WHAT'S AHEAD, FEELING ASHAMED AND EMBARRASSED

NOT TREATED AS AN INDIVIDUAL

FEELING RUSHED, FEELING UNHEARD, FEELING THEIR VOICE DOESN'T MATTER

CARRYING THE GREATER BURDEN

RESPONSIBILITY OF CARING, FINANCIAL INEQUALITY IN THE COST OF CARE AND WELL-BEING

AN OUT OF TOUCH SYSTEM

LACK OF VISIBILITY OF WOMEN, PRACTICES NOT MOVING FORWARD, LACK OF COMMUNICATION, EFFECTIVENESS & JOINED UP THINKING

MARGINALISED GROUP: CARERS

FEELING LIKE THEY ARE TREATED UNFAIRLY AND WITHOUT DIGNITY, NOT PROVIDED ADEQUATE RESOURCES



UNIVERSAL PRIORITY ISSUES & SOLUTIONS

AREAS WHERE NEEDS AND PERCEPTIONS ARE RELEVANT AND IMPORTANT ACROSS LIFESTAGES

KNOWLEDGE



GP SERVICES



MENTAL HEALTH



SCREENING SERVICES PLUS



INFORMATION CRUCIAL IN HELPING WOMEN NAVIGATE COMPLEX JOURNEYS

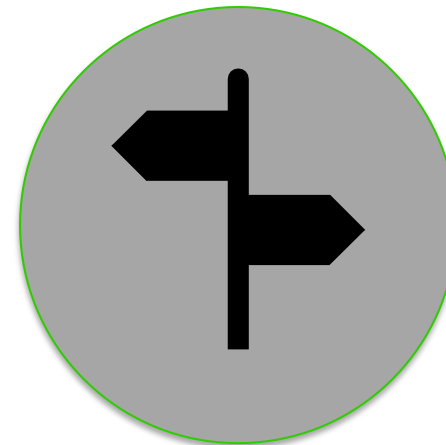
Regardless of what age, lifestage or experience women are going through they often feel unprepared – feel they don't have the facts, the basics

Feels like an unfair burden is place on women's shoulders to navigate through very complex and challenging situations

Believe that the Department has a role to play in equipping them and preparing them for the journey ahead

INFORMATION NEEDS:

- ✓ TIMELY
- ✓ ACCURATE
- ✓ RELEVANT
- ✓ USEFUL



Information is a hugely important resource for women. Many feel they have a very low baseline understanding of health in general but women's health in particular. Believe a significant opportunity exists to provide **accurate and trusted information on women's health that will guide and support women through lifestages.**



POSITIVE FOR MANY BUT ACCESS, COST AND EXPERIENCES WITH GPs IMPACT ON PERCEPTIONS AND OUTCOMES FOR SOME

NEEDS FROM THE GP EXPERIENCE ACROSS ALL LIFESTAGE

- ✓ **Time** for dialogue
- ✓ **Space & opportunity** for issues or concerns and anxieties to be aired
- ✓ **Timely access**
- ✓ **Empathy and understanding** – not transactional experiences
- ✓ **Openness** to ‘holistic approaches’ not just medication first but giving the patient tools or recommending options that might be best suited to an individual patient
- ✓ **A female doctor / nurse** – deeper empathy, a genuine interest in women’s health issues, more likely to be keeping up-to-speed with best practice in women’s health

- ✓ For many the experience with the GP is really positive – they are the **anchor point for health**, directing and supporting them when needed
- ✓ **Advocates** on their behalf
- ✓ **Listening & exploring solutions**
- ✓ **A trusted health partner through life**

CHALLENGES WITHIN GP EXPERIENCES

- × **Feeling rushed** - a ‘15 min slot’ and not truly listening to them
- × **Challenges accessing appointments**
- × **Feeling belittled or dismissed** – women spoke about sometimes being made feel like this by a male GP
- × **Feeling that a generic solution is given** – no dialogue
- × **Cost as a barrier:** €60 a significant amount of money for many and a deterrent for visiting the GP

Across all lifestages the GP is an important touchpoint. Finding ways in which the **experience with GP services can be improved** has the potential to positively impact on women’s experiences and perceptions of healthcare across all ages.



AWARENESS ONLY THE FIRST LAYER: KNOWLEDGE AND SKILLS GAP EXIST LEAVING MANY FEELING OVERWHELMED

HIGH AWARENESS OF TOPICS OF MENTAL HEALTH ACROSS LIFESTAGES

Majority believe it is a really important part of their health that needs care and attention



BUT LOW SKILLS, KNOWLEDGE AND CONFIDENCE IN DEALING WITH MENTAL HEALTH ISSUES

- Perceive mental health to be complex and layered - not confident that they fully understand 'mental health'
- Experiences and needs change by lifestage; general anxiety, stresses of parenthood, menopause, the aging process
- Do not feel they have the skills and capabilities to proactively manage or support their mental health
- Perceptions of the healthcare services shaped by anecdotal stories – typically negative in relation to access
- Few shared positives experiences with mental health services however, stigma around accessing services may have been a barrier to sharing positives

'Hearing' about issues is important to raise awareness however women feel they need **deeper knowledge**. Most importantly, women feel they need to be **given the skills and tools to take the right actions if and when needed**. Making mental health issues real and tangible by **connecting emotional needs with experiences across lifestage** has the potential to help women **navigate through the complexity of mental health**.



CONCERNS AROUND ACCESS SHAPE PERCEPTIONS OF MENTAL HEALTH SERVICES



NEGATIVE EXPERIENCES AND PERCEPTIONS OF ACCESSING HELP OR SERVICES

- Unsure of where to turn in a crisis; who are behind the 'numbers'
- Perception that GPs are not equipped to deal with mental health issues; too overwhelmed, don't have time to engage in a dialogue or may be traditional in their thinking and do not fully understand, empathise with or listen to the patient
- Delays in accessing help leading to problems and issues intensifying
- Over reliance on medication
- Lack of holistic approach – tools, skills, mechanisms to help reduce stress and anxiety

Mental Health is a high profile topic and one that is very important for women. Perceived gaps in service provision in this area impact on overall perceptions of healthcare.

PROVISION OF A TAILORED AND PROACTIVE SERVICE HIGHLY VALUED: THE ONLY INTERACTION WITH HEALTHCARE FOR MANY

Fear and anxiety around cancer is extremely high

- ✓ Pro-active and vigilant
- ✓ Provides control & piece of mind
- ✓ Time carved out to prioritise their own health

BreastCheck letter in the post welcomed – marking the 50th birthday

Even amongst women who are overwhelmed with the topic of health and well-being generally, feel that they can engage with CervicalCheck – what they need to do is clear and explicit, enabling them to part action and control

Trust and confidence in CervicalCheck was undermined and **continued effort in reassuring women that best practices are being followed is crucial**. Despite challenges screening services are viewed as an important service that provides **a unique opportunity for pro-activity**.

COMMUNICATION AND CARE OF THE PATIENT ARE CENTRAL: OPPORTUNITY TO EXPAND SERVICE TO INCLUDE AN OVERALL WOMEN'S HEALTH CHECK

EQUAL ACCESS

- The need to travel long distances to access the service creates a time barrier for women in rural areas

COMMUNICATION

- Some women, even in the 28 – 34 yr old age cohort, feel embarrassed about the procedure and choose not to engage with the service because of this – normalising the service and breaking any stigma is important

COMMUNICATION

- Communication when waiting for results or waiting for next steps can sometimes be poor, waiting without any information and updates creates anxiety and worry

CARE OF THE PATIENT

- Some women shared experiences whereby the doctor caused pain and discomfort – these types of negatives experiences negatively impact how women feel they are viewed and valued within the healthcare system

EXPANDING SERVICES

- Experience does not allow for any opportunity to check-in with health and well-being in general or for a dialogue with a professional on other women's health issues

EXPANDING SERVICES TO ALL WOMEN INCLUDING U25 YO

- Perceive lack of screening as a significant gap in the healthcare of women aged under 25 YO and crucially do not understand why they don't have access to screening



20 – 25 YEAR OLDS

ATTITUDES TOWARDS HEALTH AND WOMEN'S HEALTH FORMED AT HOME AND IN SCHOOL



HEALTH

- Attitudes and behaviours vary considerably across households
- Connection with sports in the home seen as an enabler for physical activity as is it prioritised

WOMEN'S HEALTH

- How women's health is discussed varies considerably across households – closed and open households exist



HEALTH

- × Facts and information shared but little real engagement - learning is not skills based or practical, feels detached from their reality

WOMEN'S HEALTH

- × Education on health and women's health is extremely limited
- × Taught in a very factual way; biology and anatomy
- × No opportunity for dialogue or discussion
- × Emphasis on pregnancy prevention and avoiding sexually transmitted diseases, sex as a 'sin'
- × Not preparing young women or men for the reality of what is ahead
- × Young women feel, young men are ill-formed on the basics / ignorant

Young women feel they have a **low baselevel understanding** of health and especially women's health. As they enter adult life many feel there is an **expectation** on them to understand more and take responsibility in particular in relation to sexual health. However, their **lack of knowledge leaves them feeling vulnerable and uncertain.**

ATTITUDES AND BEHAVIOURS NOW SHAPED BY MAINSTREAM CULTURE AND THE MEDIA IN THE ABSENCE OF A DEDICATED EXPERT GO-TO PLATFORM

'Health', 'well-being' and 'mental health' are something that young women feel they hear and see a lot about in mainstream culture and in social media

Without a known alternative young women rely and depend on brands, social media influencers and culture to shape their attitudes and behaviours

Many women have go-to social media sources including specific influencers who they rely on for tips, skills, practical help and information on health, well-being and mental health



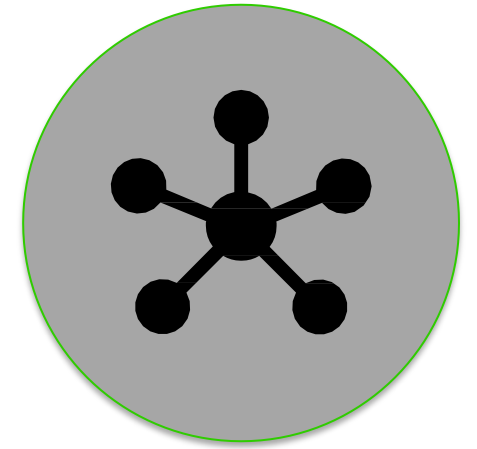
Many feel it is **social media who is driving the health agenda** in particular the conversation about mental health. While there's an awareness of the need to be cautious in relation to social media it is felt that many **personalities and brands are highly credible and are highly trusted**. Relying on social media can create challenges as the responsibility of **detangling complex health narratives and making sense of information** can be confusing. Furthermore, a reliance on mainstream media and social media also brings issues such as **body image and self-worth** to the fore.

PEER-TO-PEER SHARING OF INFORMATION IS AN UNOFFICIAL CHANNEL

Young women rely heavily on their peers for information sharing and learning about health and in particular women's health, sexual health and mental health

WHY ARE PEERS SUCH AN IMPORTANT SOURCE OF INFORMATION?

- Discomfort and embarrassment in speaking to parents
- No access to reliable trusted and informed source
- Need for empathy and understanding, feel older adults / professionals will not be able to provide
- Concern that older adults / professionals will judge them and their behaviours



The expectation that they should know more often means some don't open up and questions about what is 'normal' or 'abnormal' remain unanswered

Young women carry many questions in relation to what is '**normal**' and '**abnormal**'. They want answers to these questions and don't want to be **judged or made feel embarrassed**. Mostly importantly they want **empathy and understanding** and to be **helped navigate where they are in their health and well-being journey**.

LIMITED INTERACTION WITH HEALTHCARE: GP, ACCESS TO CONTRACEPTION OR MENTAL HEALTH SERVICES OFTEN BEGIN THE ADULT RELATIONSHIP WITH HEALTHCARE

GP



CONTRACEPTION



MENTAL HEALTH SERVICES



DISCONNECT BETWEEN NEEDS AND REALITY OF THEIR EXPERIENCES LEAVES MANY FEELING VULNERABLE AND UNCERTAIN

THEIR CONTEXT

- Feeling vulnerable and uncertain
- Lot's of questions to be answered
- Seeking out empathy and understanding
- Seeking out facts and information
- Interested in health from a holistic point-of-view



THEIR NEEDS / PREFERENCES

- Not to feel judged
- Openness and dialogue
- Time to explore questions
- 360 approach to their health and well-being
- Preference: Female GP

ACCESSING CONTRACEPTION:

- Signalling adulthood
- Taking control
- But many feel embarrassed and ashamed in relation to sex and sexual health, disguise why they are seeking contraception

THE REALITY OF THEIR EXPERIENCES

- ✓ Many spoke about really positive experiences where questions were answered and they felt confident and in control following the experience
- ✗ Interaction sometimes with a male and older GP which creates discomfort
- ✗ Transactional experience
- ✗ Directed at and not engaged
- ✗ No time or opportunity for dialogue
- ✗ Feeling awkward, embarrassed and judged
- ✗ Feeling 'childlike'

SOLUTIONS GENERATED: NORMALISING WOMEN'S HEALTH, COMMUNICATING WITH WOMEN AND PROVIDING EDUCATION THE TOP PRIORITY ACROSS ALL LIFESTAGES

NORMALISE WOMEN'S HEALTH - COMMUNICATION

- Normalise women's health by communicating on issues such as sexual health, women's health and mental health – **communicate that women are not alone**
- Create an acceptance of the conversation to help women feel **less embarrassed and ashamed**
- Ensure **information is targeted** so that it is relevant for what each lifestage is going through
- **Include younger women** in communications (Ads etc.) so that they are included and feel important from an early age

EDUCATION & INFORMATION

IN SCHOOL / COLLEGES

- **Education programme** for boys and girls in secondary level schools; Topics to include health, mental health, women's health and sexual health
- **Skills and tools based**; equip people with the tools for life
- Allow for **dialogue and discussion** as a principle of all education / information
- Engage with **3rd level / further education** to communicate health information including women's health, sexual health and mental health

ONLINE

- Create a **go-to trusted source**
- Practical information - meal prep, day-to-day diet, exercise, realistic plans
- Relevant lifestage - proactivity
- **Moderated forums** so that women are learning from experts rather than from chatting in groups, anecdotal stories
- Outline what's 'normal' and what's 'not normal', **frequently asked questions**
- Communicate through **different channels** to target the right age cohorts with relevant information
- **Social media workshops** in school to help women and men manage the pressures of social media

IN THE COMMUNITY

- **Skills based community** learning and education
- Mental health support services, discussion groups, sessions where you learn skills and how to cope
- **Healthy eating and living groups** and session where trusted information and practical knowledge are shared

SOLUTIONS GENERATED: ENSURING EXPERIENCES MEET EXPECTATIONS AND ADEQUATE ACCESS TO SERVICES IS CRUCIAL

A DIFFERENT APPROACH TO MENTAL HEALTH

- A **holistic approach to mental health** care and treatment – moving away from a medicine first approach towards treatment and care that includes counselling and learning coping skills / techniques to manage / improve mental health challenges
- Learning about mental health to start in school

FURTHER UPSKILLING OF GPs

- Ensure all **GPs are up-to-date with women's health issues** and best practice
- Increased **empathy, understanding and listening skills**
- Increased skills and training in how to deal with mental health issues
- Allow more time per patient for discussion
- Consider holistic approaches in particular in the area of mental health

ADDRESS COSTS AND AVAILABILITY OF SERVICES

- **Address the cost of women's health products**; contraception and sanitary products, make them accessible
- Free contraception for women aged 16+ years old
- Increased information on the HPV vaccine – make available outside of school if relevant for young women
- **Increase the availability of STI services and reduce costs**
- **Enable access to CervicalCheck and / or BreastCheck** or provide a clear rationale as to why not

ENCOURAGE PARTICIPATION IN SPORT

- Greater encouragement of girls to **remain active and engaged in sport** and physical activity – T.V., radio and posters encouraging women



26 – 35 YEAR OLDS

COVID-19 HAS BROUGHT ABOUT A NEW FOCUS ON HEALTH AND WELL-BEING: BUILDING MENTAL RESILIENCE IS KEY

- Most, are not encountering health issues so are not concerned about their health
- At this age many women spoke to a perception of the healthcare system shaped by anecdotal stories and what they hear in the media rather than personal experiences.
- So engagement with health and well-being is entirely self-directed and responsibility for health and well-being is entirely reliant on the individual

While the majority in this cohort are not worried about their health it is an important topic in their lives. **COVID-19 has brought a new focus** to health and well-being. Many have more time than ever before to **think about their health**, to **upskill in cooking** or to take-up **physical activity**. Building **mental resilience to cope with change and uncertainty is a focus for many**.

LEARNING AND ACCESSING INFORMATION SELF-DIRECTED: INTERPRETING THE INFORMATION CAN BE CHALLENGING

TWO MINDSETS LINKED TO KNOWLEDGE AND CONFIDENCE



CONFIDENT & ABLE

- ✓ Actively engaged in the topic of health and well-being
- ✓ Staying informed through online research, T.V. or by engaging with various resources through social media
- ✓ Feel confident and in-control
- ✓ Feel they can make good choices



FEELING OVERWHELMED

- Feel confused, struggle to interpret the volume of information into what's right for them
- Struggle to convert information into actions
- Somewhat disengaged with health, feel a lack of motivation and a lack of know-how
- For many of these women health becomes a worry and a concern because they don't know if they are doing the right things

The topic of health and well-being is really pervasive in media. Some really actively engage with the topic and feel they can take control and responsibility for their own health. For others however, **the topic feels overwhelming. For this cohort the volume of information only adds to confusion and frustration leading some to detach.**

LIMITED INTERACTION WITH THE HEALTHCARE SYSTEM UNTIL SOME WOMEN BEGIN A JOURNEY TO MOTHERHOOD

GP



SCREENING SERVICES



MENTAL HEALTH SERVICES



MATERNITY CARE



MATERNITY: NEEDS OF WOMEN AS THEY BECOME MOTHERS NOT BEING RECOGNISED



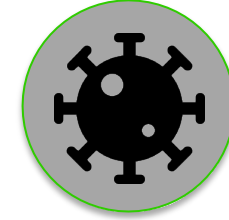
WOMEN'S CONTEXT

- Low baseline understanding of what's ahead – feeling vulnerable
- Depending on peers for information
- Feel unprepared for the realities of pregnancy, giving birth or motherhood – information provided through healthcare feels detached, traditional and doesn't prepare women for the unexpected / when things go wrong
- First time mothers feel judged and not listened to
- Expectation that they will cope
- Uncertainty creates stresses, strains and anxieties



REALITY OF THE EXPERIENCE

- ✓ Many have really positive experiences of healthcare
- ✓ Midwives and public health nurses are 'hero's'
- Feeling unheard – 'doctor knows best'
- Not given skills / tools / advice to manage new emotions or experiences
- Not engaged with / checked in on or asked how they are coping
- The mothers needs / preferences given lesser important over the welfare of the baby



IMPACT OF COVID-19

- In COVID-19 women are cut-off from the support and information sources of friends and family and felt more isolated than ever before
- Despite a heightened awareness of mental wellbeing during this time women did not feel they received any additional support

Some women have really positive experiences of maternity care. However others feel they are again left to **'figure it out'** on their own. It feels like an **unfair weight and burden** for some. The experience for some creates a sense that the healthcare system doesn't **understand needs today and that it is not staying in touch with women.**



RESTRICTIONS IN MATERNITY CARE SETTINGS DUE TO COVID-19 AN EXAMPLE OF LACK OF EMPATHY FOR WOMEN'S NEEDS

Many women shared their experiences of maternity care during COVID-19

Many were already uncertain and unsure of themselves in their pregnancies and found experiences when their partners were not allowed accompany them to be very emotionally challenging, isolating and frightening

The restrictions were perceived as a further signal that they had to go it alone in terms of their pregnancy journey and deal with issues and struggles as they arrive



WOMEN LEFT DEALING WITH TRAUMA AND GRIEF ON THEIR OWN

Women feel that loss and grief in pregnancy is **normalised / accepted** by medical professionals and society and therefore their emotional needs are not being met or supported with adequate services – counselling, grief support, coping skills

Women's experiences with healthcare professionals and with the system during these times are **extremely formative and shape perceptions of the healthcare system**

- ✓ Some felt well-cared and looked after - empathic and fully understanding of their experiences
- ✓ Directed to support services which gave them practical advice (CBT counselling)
- ✗ Many reported a lack of empathy, understanding and crucially privacy in these situations which leaves them feeling very hurt, unsupported and their loss invalidated



GREATER AWARENESS, FINANCIAL AND EMOTIONAL SUPPORT REQUIRED TO HELP WOMEN THROUGH FERTILITY JOURNEYS

- Increased awareness and conversation around the issues is perceived to be driven by health insurance companies and private clinics
- Raising the topic is seen as a positive but it also raises anxieties and concerns
- Anecdotal stories and personal experiences shared highlight the financial and emotional toll that fertility issues and fertility treatment can create
- Women feel that **a modern healthcare system should recognise the realities that women face and have in place services to meet their real needs**
- Solving for the cost of treatment and the need to travel abroad is a priority for women who have been through the experience

SOLUTIONS GENERATED: TAILORED RELEVANT INFORMATION THAT PREPARES AND EQUIPS WOMEN

NORMALISE WOMEN'S HEALTH - COMMUNICATION

- Normalise experiences of pregnancy, fertility and becoming a mother

EDUCATION & INFORMATION

IN THE COMMUNITY

- Skills based community learning and education during pregnancy and after having a baby

ONLINE

- Online resources with practical and realistic information that prepares women for the realities of motherhood
- Resources to provide practical information on general health and well-being

A DIFFERENT APPROACH TO MATERNITY CARE

- Move away from a one-fits all approach to maternity – **value the voice of the woman**
- Provide opportunities to discuss the type of care and interventions they want to receive.
- Focus on mothers as well as babies
- **Practical and holistic support** - guiding mothers on how to cope and what to do for themselves as well as their baby.
- Potential to **expand the role of the public health nurse to enable a focus on the mother**
- Greater awareness, openness and information in relation to **post natal depression – women need to understand what they can expect**, who to speak to, what supports are available and what they can do themselves. The approaches needed to consider beyond medication.
- **Community support bubbles for mums** – a bubble in the community led by a medical professional where mothers can go to meet people, share information and discuss what they are going through.
- Potential to provide increased community care opportunities for mothers

SOLUTIONS GENERATED: PROVIDING A FOUNDATION IN MENTAL HEALTH, A NEW FOCUS ON THE MOTHER AND SUPPORTING THROUGH TRAUMA

SUPPORTING WOMEN THROUGH LOSS AND TRAUMA

- Greater empathy and understanding in maternity care
- Provision of **counselling services**
- Ensure **privacy and respect** for mothers
- Increase awareness of women's health issues such as endometriosis so women can get help early

FERTILITY TREATMENT

- Provide **information** on fertility and fertility treatments
- **Reduce costs** in Ireland
- **Resolve for the need to travel**

INCREASE ACCESS AND RELEVANCE ON THE CONVERSATION ABOUT MENTAL HEALTH

- Provide factual and accurate information on mental health – **the basic facts about mental health**
- information available in **supermarkets, online resources / apps** - learnings from COVID-19 comms
- A mental health app – creates a forum to share and speak to others or have more intimate conversation with a dedicated support.
- **Opening the conversation in the workplace** – national initiatives targeted at speaking about mental health in the workplace so that the stigma is removed and the topic is normalised.



36 – 46 YEAR OLDS

MANY ARE SATISFIED WITH THEIR EXPERIENCES BUT DEEP FRUSTRATION AMONGST THOSE BATTLING THROUGH THE SYSTEM

- ✓ Many women reported being really happy and satisfied with their experiences of healthcare; acute healthcare issues, maternity care, relationship with their GP

- Deep frustration and disappointment with the healthcare system amongst some



- Looking after the needs of others – parents, partners
- Children with ongoing care needs
- Multiple experiences of maternity care that have shaped perceptions
- Experiencing health challenges

Many women within this age cohort are deeply frustrated with the healthcare system. The majority have now taken on the **responsibility of taking care of others and this weighs heavily on many**. Within the public sector many women feel they are battling through a system that is difficult to communicate with, that has considerable delays and that does not solve for the complex needs of adults or children.

CONCERNS AROUND PERSONAL HEALTH INCREASE BUT OPPORTUNITIES TO LOOK AFTER HEALTH DECREASE



HEALTH ISSUES BECOME MORE IMPORTANT

- Tackling **health issues that had been ignored** or deprioritised often related to child birth / maternity care i.e. bladder issues
- **Weight management** becomes an area of focus
- Finding time for **physical activity**, hobbies and interests
- **Proactive** prevention of hereditary conditions i.e. heart conditions, cancer



SOLVING ISSUES BECOMES MORE CHALLENGING

- **Time, energy and financial resource** goes to caring for others
- Weight management is difficult and **finding the motivation** to stay active or eat well can be draining – many yo-yo in terms of behaviour but find it difficult to keep going
- **Finding time** for physical exercise amidst the responsibilities of home and work life
- Fear and awareness of potential issues in the background cause **anxiety, worry and stress**

Juggling personal healthcare needs and the needs of others becomes increasingly different for many women within this cohort. Time becomes an extremely precious resource for women and life a balancing act. Financial resources also need considerable care – if in doubt the needs of others in accessing any type of care comes first. For some women **the role of mother** places such a burden of responsibility on women they are afraid of what will happen if they become sick.

INFORMATION ACCESSED THROUGH MAINSTREAM MEDIA: THIS COHORT HAVE BECOME THE EXPERTS AND ARE GUIDING OTHERS

Information received through the mainstream media as well as anecdotal experiences of friends, families and peers

Trusted sources – Operation Transformation, Claire Byrne

Social media plays less of a dominant role

For many in this age cohort their role has evolved to include providing information, advice and guidance to friends, sisters and daughters – **so the information they have and their experiences are shaping the behaviours and perceptions of the next generation**



This cohort are reliant on mainstream media for their information on health and well-being and are influenced by what they see. **Engage heavily with personal narratives and stories of other women's experiences.** Most importantly many within this cohort are now sharing information with younger women so **their experiences, the information and anecdotal stories they hear are shaping behaviours and perceptions of others.**

BROAD INTERACTIONS WITH THE HEALTHCARE SYSTEM

HEALTHCARE SYSTEM



MATERNITY CARE



MENTAL HEALTH



GP



SCREENING SERVICES



SOLUTIONS GENERATED: SOLVING THE MACRO HEALTH NEEDS A HUGE PRIORITY FOR MANY

RESOLVE WAITING TIMES

- Access to services – waiting lists across a very broad spectrum of services are viewed as considerable challenges as they delay diagnosis, access to further services or the appropriate care.

ENSURE JOINED-UP THINKING IN RELATION TO SERVICES

- Joined up thinking across care – there is a sense that some issues can fall between the gaps if there is not absolute clarity in terms of approach. Examples were provided in relation to gaps in services across maternity and gynaecological services.

IMPROVE COMMUNICATION WITHIN HEALTHCARE

- Lack of information when in the system – women feel that when they are ‘in the system’ they are not adequately informed as to next steps, processes, expected timeframes etc. Women feel they are left in a vacuum without access to the information they need to feel reassured or cared for.

SUPPORTS FOR PARENTS

- Support parents in recognising early signs and symptoms of children with special needs

SOLUTIONS GENERATED: TAILORED COMMUNICATION AND DEDICATED SERVICES

EDUCATION AND INFORMATION

- Education for the younger children – information in schools, sexual health, checks as a child grows, preparing young women, where they can go and how they take care of themselves
- Empowering younger woman – help them along, end the taboo
- TV shows about motherhood, open communication, making ok to ask questions

COMMUNICATE IN WAYS THAT ARE RELEVANT TO WOMEN

- Storytelling and spokespeople rather than information on leaflets
- T.V. shows on mainstream media
- Ads on T.V., social and radio

TAILORED WOMEN'S HEALTH SERVICES

- Dedicated women's health doctors who are experts, preferably female, and who have the time to talk and discuss key issues with women.
- An annual women's 'CHECKIN-IN' – a full annual health check that explores a wide range of women's issues and ensures all is ok. Potentially an opportunity to incorporate this with screening services.
- Increased advertising in relation to BreastCheck and CervicalCheck – women need to be informed about that these services exist and the importance of accessing these service

WOMEN'S HEALTH IN THE COMMUNITY

- Community check-in clinics or a community women's health nurse – Currently the focus of care is entirely on the baby. Women do not feel that important issues like post-natal depression and just learning to cope with a new baby are being adequately addressed and that women are left on their own to get through the experience as best they can.
- Motivate people in relation to general health and well-being - Healthy Ireland it's not about getting fit but healthy, start at the basics, bring health into schools, beyond physical health, body awareness
- Create a support network for women so they can discuss crucial issues



46 – 60 YEAR OLDS

ENTERING A CHALLENGING LIFESTAGE WITH A LOT OF CHANGE AND UNCERTAINTY AHEAD

- Time and opportunity to tackle issues which were left lapse as children are less dependent now
- Hoping for a new lease of life and a renewal

- × Health issues or challenging family situations have become entrenched and their own health has been further de-prioritised
- × Identity struggle; Isolating and lonely period as their families grow up and move on and they have to reconnect with hobbies, interests and pursuits that they had set aside
- × Facing into the next health journey of menopause
- × Many feeling hugely uncertain and anxious about menopause

Facing into the menopause can be a **daunting experience** for many women. For many their **knowledge is based on anecdotal stories** and they are anxious about the physical and emotional experience ahead. **Women want to get ahead of it and take control.**

INTERACTIONS WITH HEALTHCARE ON SPECIFIC TOPICS

MENOPAUSE



GP



SCREENING SERVICES



MENOPAUSE A SECRETIVE TOPIC THAT IS NOT SPOKEN ABOUT BY ANYONE



Low baseline understanding of menopause entering this lifestage

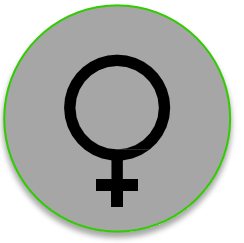
Depending on mothers, older sisters or very close friends to provide information and guidance but for many the topic is extremely **personal and sensitive**

For many women the topic of menopause feels **secretive and closed**;

- × Not discussed on mainstream media
- × Not discussed within their peer groups
- × Not discussed in the workplace

The lack of communication on the issue of menopause creates a **taboo and stigma**. It also creates an atmosphere in which women feel a sense of **loneliness and isolation**. For some there is even a sense that women are **no longer valued by society** or by the healthcare system once they are finished having children. Menopause is truly seen as a taboo that women are expected to go through alone, unsupported and in silence.

RIDICULED AND LAUGHED AT BY SOCIETY: EMOTIONAL AND MENTAL HEALTH NEEDS DISMISSED



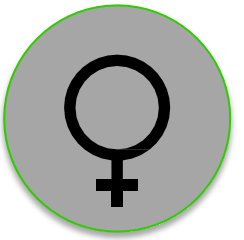
The experience of going through menopause is physically challenging for many

However, the emotional burden it can create and the impact on mental health can place women under significant stress and trauma

However, the taboo and stigma around menopause means that when women are at a low point and need guidance, support, practical information they are **ridiculed and laughed at by wider society**

Women feel unsupported by society when some are at a very low point.

HEALTH ISSUES OLDER WOMEN FACE NOT DISCUSSED AND BEST PRACTICES NOT EVOLVING



Beyond menopause there is a sense of a disinterest in women's health issues for older women i.e. bladder issues, pelvic floor issues

Some feel they there is an expectation for women of a certain age to simply **accept their lot and to get on with things**

Many women are surprised that women who are mothers are even today not given the accurate information or practical advice in order to prevent common issues such as pelvic floor issues

This signals **a lack of evolution in thinking and practices in relation to the area of women's health**



SOLUTIONS GENERATED: TACKLING THE TABOO OF MENOPAUSE AND PROVIDING REAL SUPPORT CRUCIAL

TACKLE THE TABOO OF MENOPAUSE

- Dedicated education and information in relation to the menopause – helping women understand what’s happening to their body, what’s normal and the proactive approaches they can take to improve their health.
- GPs / community nurses who are experts and specialists in women’s health including menopause etc.

WOMEN’S HEALTH IN THE COMMUNITY

- Creating ‘Women’s Hubs’ similar to Men’s Sheds – community based, regional access, opportunity for experts and guest speakers to attend
- Pop up community women’s health clinics – similar to the mobile BreastCheck clinics, clinics should provide not just an opportunity to visit a nurse / doctor but also an opportunity for open discussion with other women about topics such as menopause etc.
- A women’s health clinic that becomes a ‘One Stop Shop’ for women’s health needs – the clinic should be community based and provide a broad remit of services from screening to physiotherapy. The clinic should be consist mostly of female doctors and nurses to ensure there is a real focus on women’s health and that the ethos of the clinic is around empathy and understanding.

EDUCATION AND INFORMATION

- A lifelong approach to learning about health and well-being – education should begin in school and continue in some form throughout life. Transition year in school presents a particular opportunity for learning



60+ YEAR OLDS

HOW WOMEN VIEW THEMSELVES IN SOCIETY HAS EVOLVED CONSIDERABLY

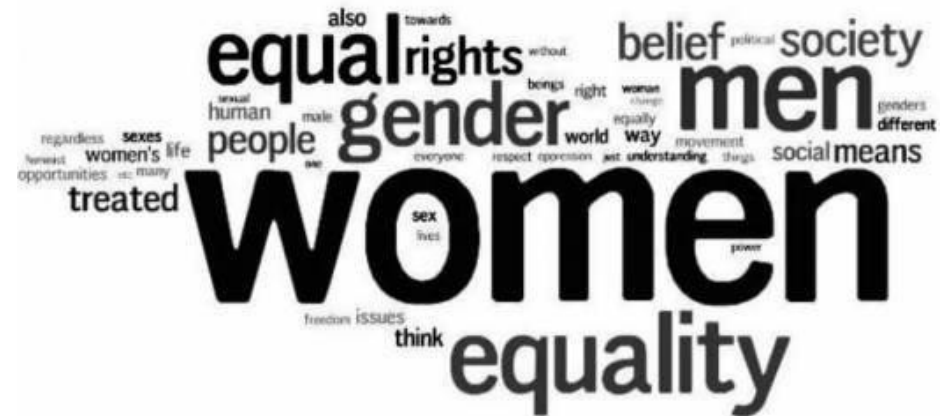
View healthcare and women's health through the lens of the changes that they have seen

Reflect on a system that was patriarchal but slow paced

A closed off Irish society meant women were silent

To many, women have achieved far more rights and have place a far **greater value on themselves than ever before**

Some think that expectations have gone too far

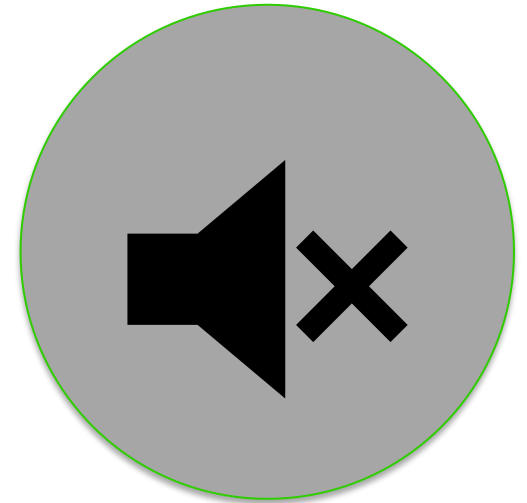


THE LEGACY OF SILENCE HAS IMPACTED ON WOMEN'S ABILITY TO USE THEIR VOICE

Many women at this lifestage find it very challenging to articulate their needs and experiences

They feel they **do not have the language or the confidence** to interact and engage with healthcare professionals and can accept what is being told to them while being **very frustrated but remaining silent**

In some sense women within this lifestage can be **passive in relation to their healthcare needs**



SIGNIFICANT CARING DUTIES CONTINUE FOR SOME

While connection to grandchildren and family is hugely important there are some who feel their children have become **dependent on them as a childcare resource**

Many feel that while physically they may not be able to keep up with the demands of looking after children they are obliged to help their children

This has a physical impact on wear and tear on the body

However it does support emotional well-being for some



STAYING ACTIVE, INDEPENDENT AND CONNECTED KEY PRIORITIES FOR THIS COHORT

PRIORITY NEEDS

Staying active, well and independent is a priority for this cohort



SOLUTIONS AND INTERVENTIONS TO SUPPORT THESE NEEDS:

Access to services that facilitate this:

- Access to care within their local community
- Aftercare post surgery / injury etc.; Cost currently a barrier to access
- Continued focus on prevention - access to dexter scans
- Physiotherapy and other occupational care
- Upskilling on technology to stay connected



CARERS

EMOTIONALLY EXHAUSTED; STRUGGLING TO COPE

- Emotionally exhausted and drained

- COVID-19 has further exacerbated stress and challenges in households
- Supports have / were significantly reduced or temporarily suspended

- When an adult or child in the family has ongoing care needs the entire family is impacted
- Huge concern amongst carers for the lifelong impact on siblings and others in the household

Some participants were openly **crying and very upset** during the forum as they shared their experiences. Some spoke of incredibly low points, feeling exhausted from their everyday experiences and everyday challenges.

ANGRY AND HURT AT HOW THEY FEEL THEY ARE BEING TREATED

Many carers are extremely angry at how they are treated

- × Extremely limited counselling or support to deal with their trauma
- × Extremely limited training in how to be a carer; carrying out complex tasks
- × Income support received is perceived as insufficient and places carers and their family in poverty
- × Some women are left financially dependent on partners / husbands which leaves them extremely vulnerable
- × Feel like there is no recognition, financial or other, of the hugely demanding and important role carers play in society
- × Supports in place are not adequate for many; do not provide the necessary respite
- × Continuity of care / wrap around services are difficult to access
- × Feel like they are battling through a bureaucratic system; believe sees them as a drain on the system, always seeking more when they believe they are just looking for the basics to survive; responsibility for carers moving to Department of Social Protection a signal of this

Carers are extremely angry at how they feel they are being treated. Many feel they are living a 'life sentence' and instead of being given the support they and their families need they are **treated with 'contempt'**.

INSUFFICIENT RESOURCES TO LOOK AFTER PERSONAL HEALTH

Carers feel they are **unable to look after their personal healthcare needs**

Feel they do not have the adequate support to enable them to address their own healthcare needs – time and financial resources are the most significant barriers

Fear of getting sick and being unable to support a child / partner is terrifying

Carers are fearful of getting sick and what this could mean for their family. However, **looking after themselves does not feel possible for many because of time and financial resource issues.**

ENABLERS MUST BE IN PLACE FOR CARERS TO HAVE THE CAPACITY TO LOOK AFTER THEIR PERSONAL HEALTH

PERSONAL HEALTH PRIORITIES:

- Pain management; back pain etc.
- Physical therapies; physiotherapy etc.
- Counselling; Trauma counselling that is ongoing
- Training; official training channels
- Mental health supports for the full family, in particular siblings

ENABLERS / PRIORITIES FOR REVIEW:

- Carers medical card
- Delivery of continuity of care for the patient; view each patient and their needs on an individual basis, ensure the patients full needs are considered and solved for within an efficient system
- Increase payments to carers – reflect the value of the work they do, bring them out of poverty
- Ensure respite and support resources (medical staff) adequately meet the need of the family
- Recognition of physical abuse faced by carers; supports to be put in place when required

In order for carers to look after their own health they believe they need the necessary resources (time and financial) and supports (respite, assistance from trained medical professionals / nurses) must be in place for their loved one. **Without these sufficient enablers women who are carers feel they will not have the capacity to look after their own health.** Carers priorities needs are different. Many are physically and emotionally worn out and need solutions and interventions that tackle these issues and help them in their day-to-day.



EXECUTIVE SUMMARY

FOR MANY EXPERIENCES WITH HEALTHCARE ARE POSITIVE

FACTORS THAT SHAPE POSITIVE EXPERIENCES FOR WOMEN

MATERNITY
CARE

LISTENING AND EMPATHY, RIGHT SERVICES, AFTERCARE, ENGAGEMENT
WITH THE MOTHER

GP
SERVICES

DIALOGUE, PROACTIVITY, OPEN AND TRUSTED RELATIONSHIP WITH GP

ACUTE
CARE

EFFECTIVE COMMUNICATION, RIGHT SERVICES, AFTERCARE, POSITIVE
OUTCOMES, EMPATHY

SCREENING
SERVICES

ACCESS TO SERVICES, PROACTIVE, TAILORED FEMALE CENTRIC SERVICES

WOMEN FEEL THE HEALTHCARE SYSTEM IS UNDERSERVING THEIR NEEDS

WAYS IN WHICH WOMEN BELIEVE THEIR NEEDS ARE BEING UNDERDELIVERED

LIMITED INFORMATION & CONVERSATION

FEELING UNSUPPORTED, NOT KNOWING WHAT'S AHEAD, FEELING ASHAMED AND EMBARRASSED

NOT TREATED AS AN INDIVIDUAL

FEELING RUSHED, FEELING UNHEARD, FEELING THEIR VOICE DOESN'T MATTER

CARRYING THE GREATER BURDEN

RESPONSIBILITY OF CARING, FINANCIAL INEQUALITY IN THE COST OF CARE AND WELL-BEING

AN OUT OF TOUCH SYSTEM

LACK OF VISIBILITY OF WOMEN, PRACTICES NOT MOVING FORWARD, LACK OF COMMUNICATION, EFFECTIVENESS & JOINED UP THINKING

MARGINALISED GROUP: CARERS

FEELING LIKE THEY ARE TREATED UNFAIRLY AND WITHOUT DIGNITY, NOT PROVIDED ADEQUATE RESOURCES

THREE PRIORITY AREAS FOR CONSIDERATION TO IMPROVE WOMEN'S EXPERIENCES IN HEALTHCARE

1

MAKE WOMEN'S HEALTH PART OF THE CONVERSATION



- Remove the taboo and stigma
- A national, open discussion
- Communicate in channels that are relevant
- Topics relevant to lifestage
- Storytelling narrative
- Provide trusted, accurate, expert information

2

EDUCATE AND INFORM



- Equip women and men with knowledge and tools
- Lifelong learning
- Skills based learning
- Community based learning
- Continue to evolve best practice on women's health within healthcare
- Keep in touch with women's needs

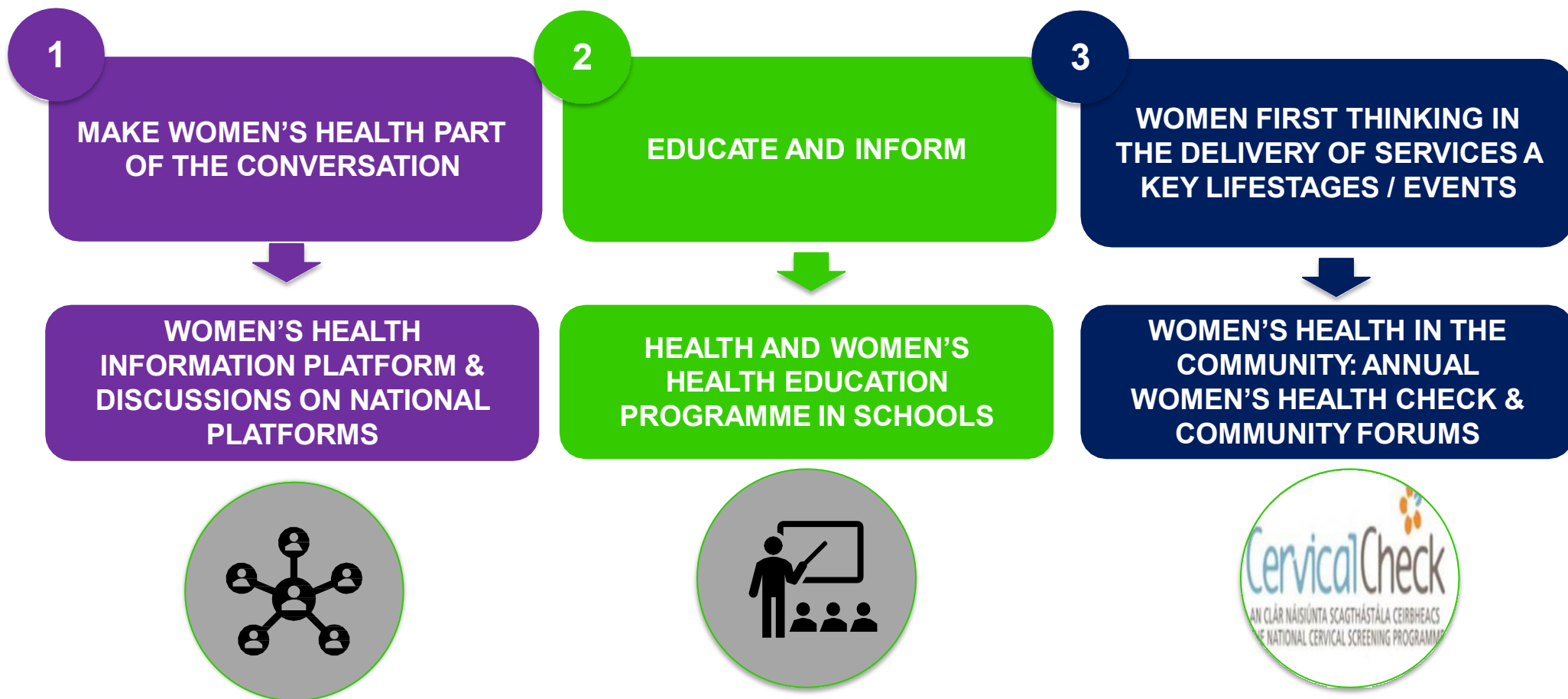
3

WOMEN FIRST THINKING IN THE DELIVERY OF SERVICES



- Provide resources that support and enable in their journey
- Proactivity and prevention as the cornerstone
- Bring women's health into the community
- Bring best practice & holistic health thinking to every interaction

THREE BIG IDEAS GENERATED BY WOMEN TO IMPROVE THEIR HEALTH JOURNEY AND EXPERIENCES WITHIN HEALTHCARE



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MCCCP

The Independent Strategy Agency

Thank You