

# The Gendered Experience of Mesothelioma Study (GEMS)

**12 Kings Bench Walk International Women's Day Webinar**  
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# The Gendered Experience of Mesothelioma Study (GEMS)

Why focus on the gendered experience?



## **Aim**

To explore men and women's experience of mesothelioma in order to understand similarities and differences e.g. awareness of mesothelioma, risk and exposure, presentation and diagnosis, access to treatment and compensation and legal processes



# Project summary

## Design

Stage 1: Statistical analysis of national data

Stage 2: Qualitative interviews and analysis

Stage 3: Testing out the findings with key stakeholders and focus groups

# Today's presentation



THE DEFINITIVE GUIDE TO RELATIONSHIPS

**MEN ARE  
FROM MARS,  
Women Are  
from Venus**

JOHN GRAY

OVER 15 MILLION COPIES SOLD WORLDWIDE



## HASAG data set



- Cases from 2016, 2017, 2018.
- 1177 mesothelioma cases
  - 82.5% were men (971)
  - 17.5% were women (206)

# HASAG data findings

- **Age** - Both men and women are in mostly in the 71-80 year group at diagnosis. (42% vs 44%).
- There are more very young women in the cohort (5% of women are under the age of 50 compared to only 0.5% of Men).
- **Next of Kin** - Fewer women had a next of kin (75%) vs men (82.5%).
- Fewer women had a spouse/partner (46% vs men 63%).
- **Type of mesothelioma** - Majority of cases were pleural (99%) and 1% of cases were peritoneal.
- Women were more likely to have peritoneal (4% of women vs 1% of men).

# Proportion who said they are **Going to Call** and **Called** a Solicitor (3 years).

## Men:

89% → 87%

82% → 79%

77% → 75%

## Women

80% → 70%

63% → 58%

53% → 51%

## What does it mean

- Percentage of both men and women who are *Going to Call* decreases over the 3 years
- The trend is same for men and women
- Number of men has dropped by 12% vs 27% women.
- The % of Women who seek legal advice has dropped by nearly 20%.

# Occupational Risk

- Our findings show that the high risk population for Men is Construction (*Carpenter, Joiner, Plumber, Electrician*) whereas high risk occupation for Women is *Admin, Teacher, Health Services*.
- For women, admin is the High Risk Occupation in this data set (29%), health services (nurse/lab), (10%), teacher/school (10%), Retail ( 6%), Factory ( 7%).





## Interview participant demographics

11 women and 13 men

- Age: 31-79
- Living circumstances: Single, living together, divorced, married
- Location: Across England and Scotland
- Length of time living with mesothelioma: 5 months – over 5 years
- Occupation

# Being practical at diagnosis



“My response to my diagnosis was to come home and to chuck everything out, and I took down the net curtains, because I said well, **men don't wash net curtains** [...] I bought everything new, so when I was gone there was nothing he had to buy.” F1, Amy

“I do all the bills, I do everything in the house as far as the running of it, if you like. So I've got to try to start getting her to do all the banking, all the money, all the bills, that part of it.” M4, Derek

# Control and treatment

**“I’m happier sort of being told what to do. I’m not very good at making decisions” F3, Cath**

**“my quality of life is more important. So I’ll be telling them to stick their chemo where the sun doesn’t shine and I will carry on being well and look after myself.” M8, Ivan**

# Risk perception



“Interviewer: And what about when they started asking questions in the hospital about asbestos exposure? How did you feel about that?”

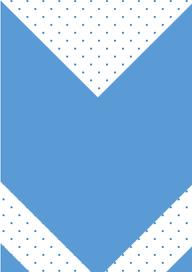
Fred: A sort of **inevitability**” M6, Fred

“R: Somebody said to me, have you worked with asbestos, and I said no ‘cause I thought, well what a **stupid question** really, you know? I would never have dreamed that I would have got it” F6, Fiona

“I was a setter’s mate. [...] there was asbestos all around the burners. But I didn’t know all that, I’d gone into all that myself and realised that’s where the asbestos was. I’ve only just really been looking at it. So, I didn’t know really until about two years ago that there had been a case that won. So, there was a case. I only found out through another support group that said to me ‘oh yeah, we’ve had a case.’”  
F1, Amy



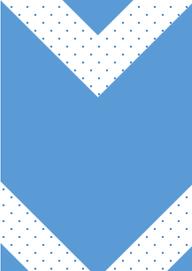
# Key points from the data



- The importance of a sense of control at diagnosis may differ between men and women. This difference may have implications for patient priorities and the delivery of health care



- Women and men may have different priorities during their mesothelioma journey e.g. treatment trials and finances.



- Women may lack awareness of the risk of exposure and asbestos related diseases. The nature of exposure to asbestos may be different. Therefore, we may need to consider occupational risk differently for men and women.



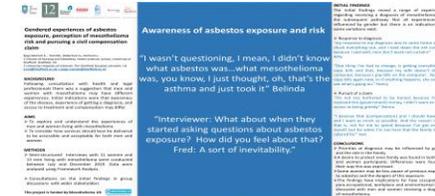
- Women may be less likely to seek compensation. This could be due to lower awareness amongst women and a higher sense of entitlement amongst men.

# What next?

## Sharing GEMS findings Presentations



## Posters



## Publications and reports





**MESOTHELIOMA UK**

Supporting People With This Asbestos Cancer

# Mesothelioma UK Research Centre - Sheffield

Established in 2020, the Mesothelioma UK Research Centre - Sheffield conducts a portfolio of robust and rigorous research with a reputation for excellence nationally and internationally.



Led by Professor Angela  
Tod and Dr. Clare  
Gardiner

Launched  
November 2020



## The Vision

The **Mesothelioma UK Research Centre** will conduct a portfolio of robust and rigorous research with a reputation for excellence nationally and internationally

## Projects

- Rapid review of evidence on mesothelioma patient and carer experience
- Mesothelioma and schools/education
- Peritoneal mesothelioma
- Impact of COVID on patients and staff
- The Experience of Long-term Survival in People Affected by Pleural Mesothelioma and Their Carers. (Matt)
- **Research prioritisation exercise**

Please contact us for:

1. Research ideas
2. To participate in the Research prioritisation exercise
3. To be in contact with the Mesothelioma Research Centre – Sheffield

[a.tod@Sheffield.ac.uk](mailto:a.tod@Sheffield.ac.uk); [c.gardiner@Sheffield.ac.uk](mailto:c.gardiner@Sheffield.ac.uk)

# Thank you for listening

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