

Women's experience of hyperemesis gravidarum: results of self reported online surveys.

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Dr Margaret O'Hara

- Medical physicist, currently working as Research Fellow at University of Birmingham
 - Current (paid) research area: breath analysis for investigation of liver disease
- Former HG sufferer, (mother and 2 sisters also suffered HG, total of 14 pregnancies, all HG).
- I had excellent treatment for HG at BWH, in contrast to sisters whose 'treatment' ranged from appalling to adequate
- PSS volunteer since 2010
- HG research self funded – motivation to improve treatment for daughter and 3 nieces

Founding of PS-SOS

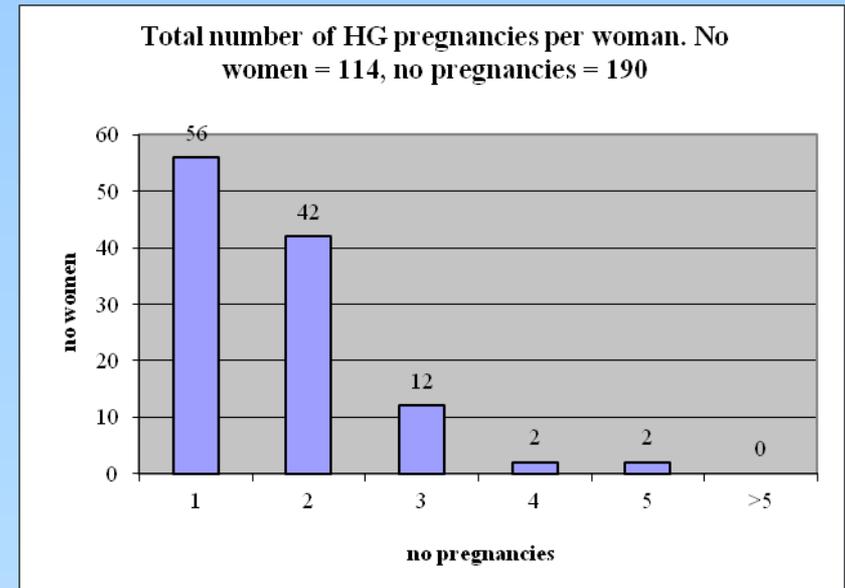
- I had done my own research on HG before becoming pregnant
- In 2010, I joined the mumsnet hyperemesis support group and discovered that for many women, things are not much better than in 1965
- I wrote to mumsnet and helped them to rewrite their information pages on hyperemesis
- Copy formed basis of PS-SOS
(www.pregnancysicknesssos.co.uk)
- PS-SOS focuses specifically on HG provides
 - tips on coping with HG from other women's experiences
 - research abstracts and treatment protocols

Online Survey on PS-SOS in 2011/2012

- Survey on PS-SOS (pregnancysicknesssos.co.uk)
- Women principally recruited from
 - HG and PSS Facebook group
 - mumsnet hyperemesis support threads
- Responses June 2011 – June 2012

Respondents' Characteristics

- respondents **n = 114**
- Total pregnancies reported **n = 229**
 - HG pregnancies **n = 190**
 - Non-HG pregnancies **n = 39**
 - Miscarriages = **31** (17 wm 14% of pg, 15% of wm)
 - Terminations = **9** (6 wm, all attributed to HG, 5% of wm, 4% of pg)
- HG pregnancies per woman
 - mean = **1.7**
 - range **1- 8** (inc miscarriages, max 5 live births)
- pregnant at time of responding **n = 63**
 - mean 19 weeks
 - range 5 – 40
- age during HG pregnancy **30 years (16-42 years)**
- Nation of Residence - **UK (98)**, The Netherlands (5), Norway (3), USA (3), Israel (2), Australia (1) and Malawi (1).



Awareness

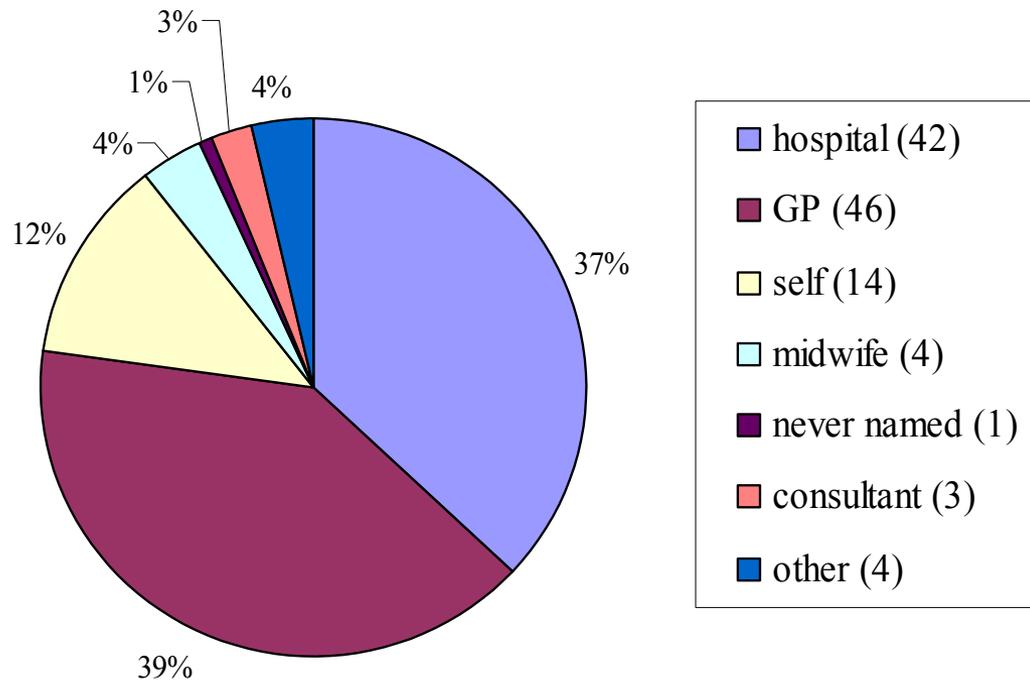
- Had you ever heard of HG before diagnosis?
 - **Yes - 26%** (29) No - 74% (84) N/A – 1
 - relative (6) is or knows an HCP (6), knew sufferer (5) self research (4), pregnancy book (4), radio (1), magazine (1), knew about Charlotte Bronte (1)
- Have you encountered people who don't understand your condition and assume it's simply 'morning sickness'?
 - **Yes – 92%** (104) No – 8% (9) N/A – 1
- Have you been advised to try ginger, crackers, seabands etc?
 - **Yes - 96%** (110) No – 3% (3) N/A – 1
 - everyone (50), friends (41), relatives (29), other HCP (29), GP (26), midwife (22), colleagues (9), internet (5)
- If you work, were your employers sympathetic to your condition? (UK only n=72)
 - **Yes – 78%** (56) No – 22% (16)

Risk Factors

- Previous occurrence
 - **68% (51) had HG in every pregnancy** (of 75 who had had > 1 pregnancy).
- Family History – Do you have relative with HG (n=105)
 - **Yes - 35%** (37) (23 m, 10 s, 9 gm, 5 c, 6 a all maternal except one gm)
 - No - 65% (68)
 - (Don't know 8% (9))
- Female Foetus (n = 88, 125 pregnancies where gender known)
 - 59% (74) female
 - 41% (51) male

How were you diagnosed? n=113

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How many weeks pregnant when diagnosed?

mean **9 weeks**
range 3 – 38

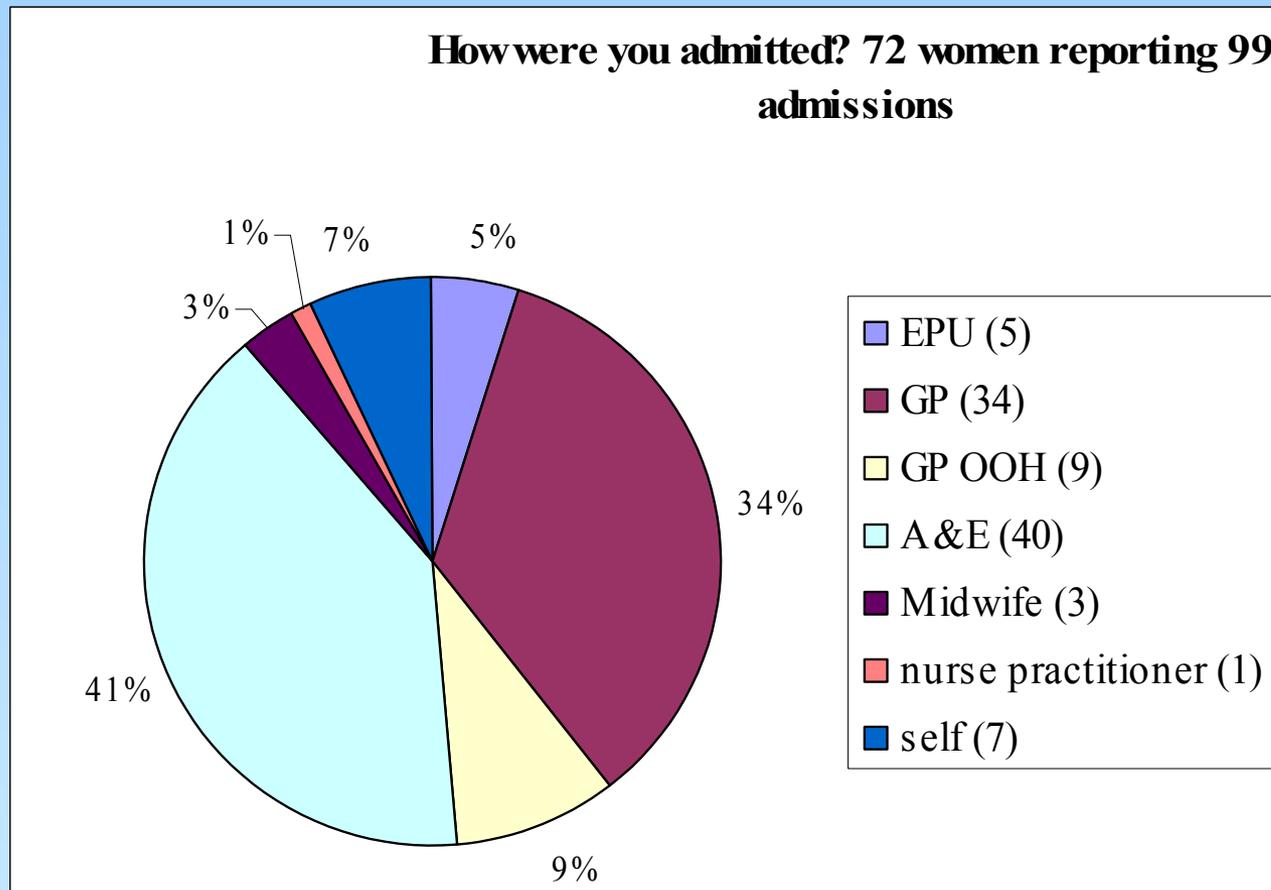
*some women never received a diagnosis

How many weeks ill before diagnosis?

mean **4 weeks**
range 0.5 – 37

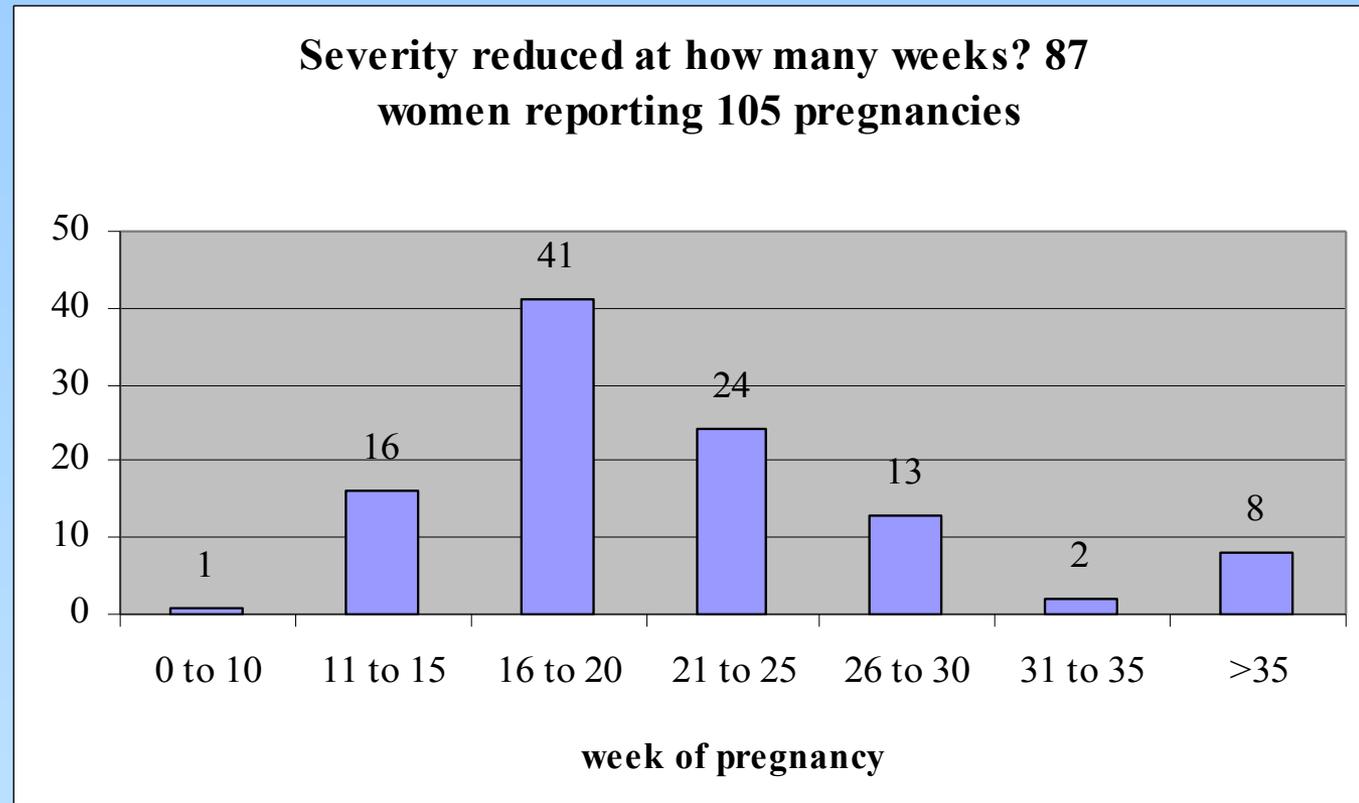
Were you admitted for IV fluids If so how? (UK respondents only n = 98)

Yes 72
No 26
n/a 1



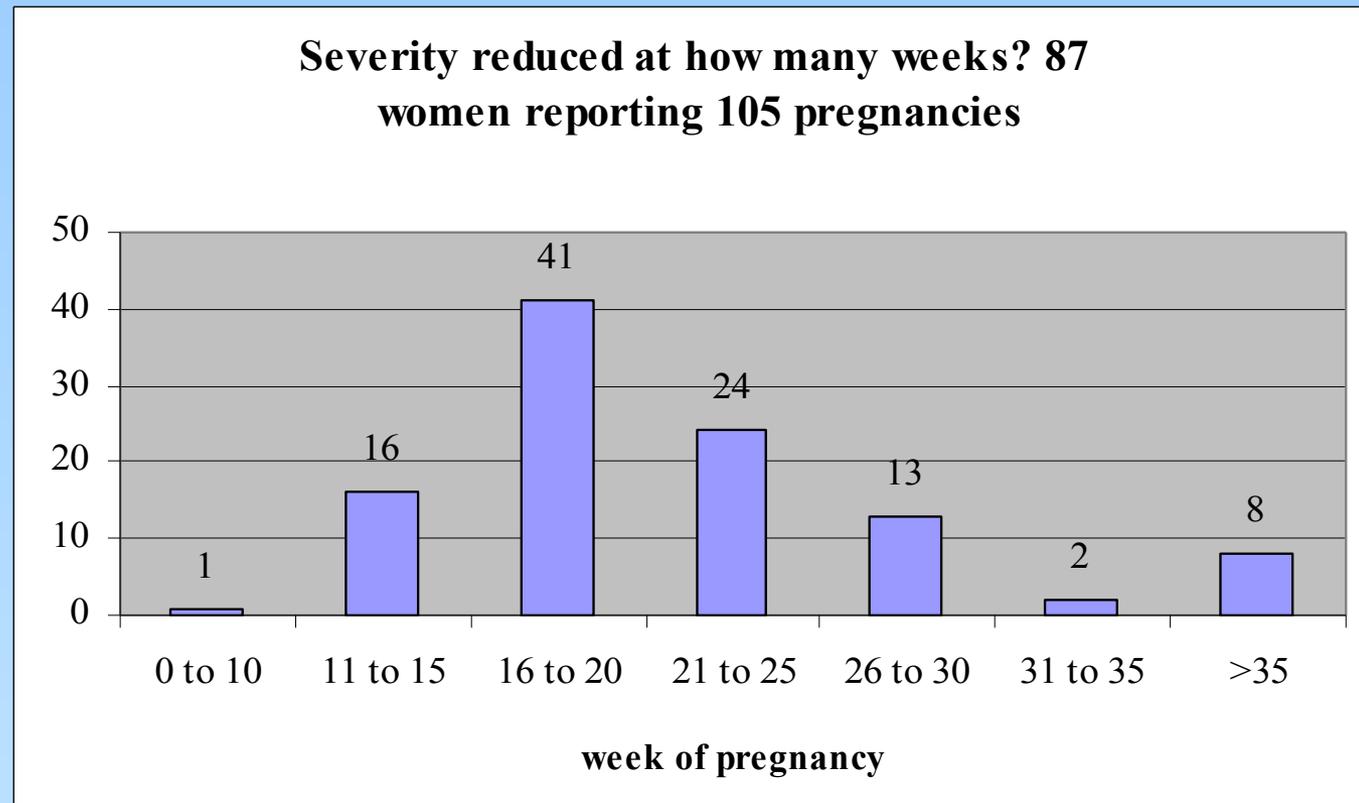
Symptoms reduced at how many weeks?

mean **21 wk**
range **10 – 40**
n = 87,
pregnancies = 105



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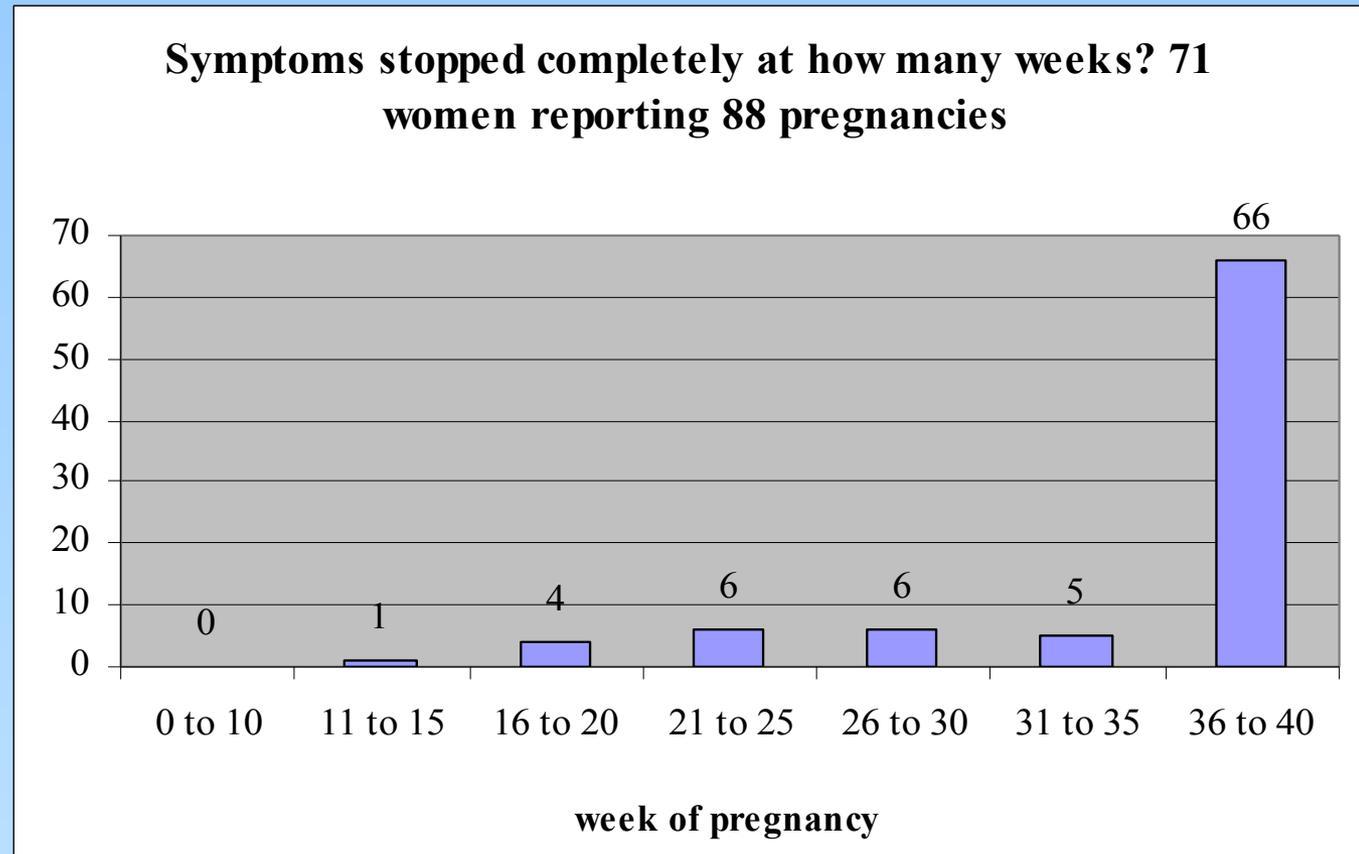


Severity reduced by 14 weeks in only **12%** (13) of pregnancies.

Severity reduced by 22 weeks in **65%** (68) of pregnancies

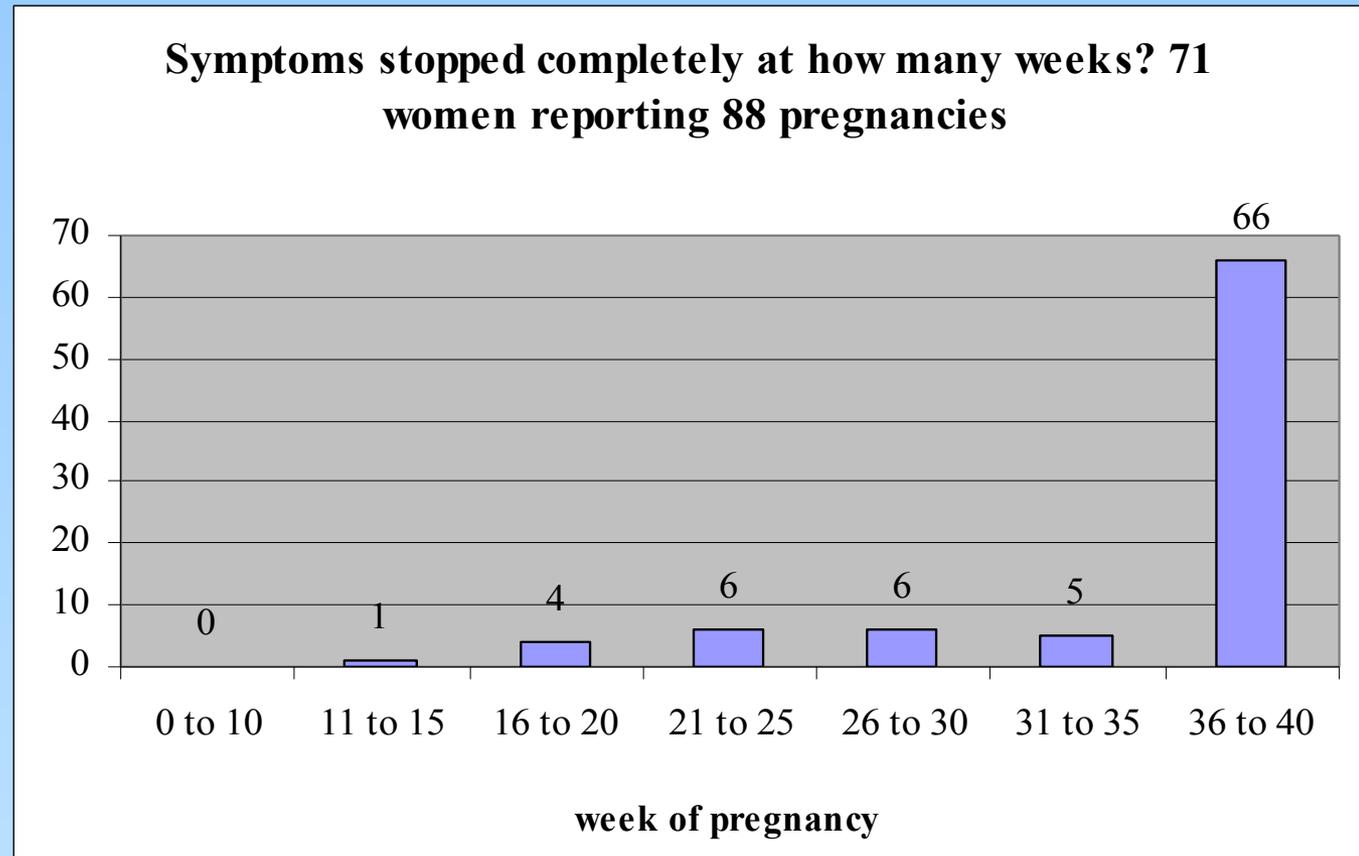
Cessation of Symptoms

mean **36 weeks**
range **14 – 42**
n = 88,
pregnancies = 71



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Symptoms stopped by **14 weeks** in only **1%** (1) of pregnancies.

Symptoms stopped by **22 weeks** in only **9%** (8) of pregnancies

Symptoms lasted till birth in **68%** (60) of pregnancies

HER survey indicates that 46% of women report nausea and vomiting go away after 30 weeks.

What does the literature say?

“The characteristic time-course of severe hyperemesis is not well-recognised. It universally manifests before eight weeks gestation (usually 4 – 6 weeks), is at its worst early in pregnancy and spontaneously remits in over 80% of women between 14 and 22 weeks (remitting hyperemesis).”

Al-Ozairi et al. “Termination is not the treatment of choice for severe hyperemesis gravidarum: Successful management using prednisolone.” Obstetric Medicine 2009

This paper is referring to a sub-cohort of women who do not respond to conventional antiemetics, requiring steroids to reduce vomiting. The use of the word ‘remit’ in this context means the lifting of the nightmarishly horrendous continuous vomiting. It was not intended to suggest that all symptoms cease. 20% of women continue to need steroids and their illness is described as unremitting. From personal communication with **Dr Roy Taylor, Newcastle Royal Infirmary**

Which medications worked?

- **94%** of respondents had used medication (1 – 6 different drugs)
- **No ratings**, medication included as successful even if reported that it only worked somewhat.
- Mostly **oral** though some IV
- **Ondansetron** by far most successful

	tried	helped	didn't help (tried minus helped)	success rate
cyclizine (valoid)	64	39	25	61%
prochlorperazine (stemetil, buccastem)	47	17	30	36%
metoclopramide	45	23	22	51%
ondansetron (zofran)	43	36	7	84%
promethazine (phenergan, avomine)	21	7	14	33%
domperidone	12	4	8	33%
ranitidine	12	7	5	58%
steroids	8	5	3	63%

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- Mostly **oral** though some IV
- **Ondansetron** by far most successful
- Findings at odds with *Sullivan, C. A., et al. (1996). "A pilot study of intravenous ondansetron for hyperemesis gravidarum." American Journal of Obstetrics and Gynecology 174(5): 1565-1568.* who found ondansetron no better than promethazine
- However Sullivan et al
 - only compared IV medication, perhaps promethazine poorly absorbed orally
 - Sample size small only 15 in each group

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domperidone	12	4	8	33%
ranitidine	12	7	5	58%
steroids	8	5	3	63%

What else helps eg ginger, seabands (apart from pharmacological medication)?

nothing	40%
rest	32%
Dietary measures*	19%
acupuncture	9%
avoid motion	9%
Avoid triggers	7%
Mind control/meditation/ hypnotherapy	6%
seabands	5%
Vitamin B12	2%
homeopathy	2%
contact with other sufferers	2%

*Diet means interventions such as frequent eating, particular foodstuffs

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Does Rest Help? –
when asked explicitly

Yes – 91% (104)

No – 4% (5)

N/A* – 4% (5)

*these women were unable to
get out of bed so weren't
able to say if rest helped.

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frequent eating, particular foodstuffs

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**Not one single
woman reported
that ginger was
beneficial**

*Diet means interventions such as
frequent eating, particular foodstuffs

Describe your experience of your GP, were they sympathetic, knowledgeable, willing to prescribe

Only includes answers from women in UK, n = 98

**Women who found
a GP who was
effective at treating
HG**

Yes – 37

No – 56

*Answers interpreted
from long text replies*

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Only includes answers from women in UK, n = 98

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Yes – 37

No – 56

Answers interpreted from long text replies

	Number of GPs of that description	Number of women finding a GP of that description
GP sympathetic	81	65
GP unsympathetic or dismissive	60	51
GP knowledgeable	43	37
GP not knowledgeable	65	52
GP willing to prescribe without consultant advice	56	48
GP didn't prescribe or delayed prescription	39	33
GP prescribed after consultant instruction	20	17

Did you see a consultant obstetrician?

Only includes answers from women in UK, n = 98

Yes – 38

No – 52

N/A - 8

Route for referral	number of women	% of those referred	% of total
A&E	12	32%	12%
MW	9	24%	9%
other*	7	18%	7%
GP	5	13%	5%
EPU	3	8%	3%
HG clinic	1	3%	1%
not said	1	3%	1%

*Other includes women who were already seeing a consultant for other complication of pregnancy

Words used to describe GPs

Negative words	
not knowledgeable	14
unsympathetic*	12
dismissive	11
unhelpful	4
uncaring	4
not understanding	3
useless	3
negative experience	2
negligent	2
fobbed off	2
not good	2
horrible, appalling, cruel, horrendous, disappointing, shocking, poor, insensitive, shit, sarcastic, rude, ignorant	all one each
Total	71

Positive/neutral words	
sympathetic*	35
helpful	5
understanding	5
knowledgeable	4
great	4
fantastic	4
good	3
amazing	2
excellent	2
reassuring	2
very good	2
supportive	2
fabulous	2
wonderful, brilliant, comforting, supportive, ok, caring, super, kind	all one each
Total	78

*10 sympathetic but ineffective,
2 unsympathetic but effective

Words used to describe HG

Description of HG or how it made them feel	Number of women reporting each descriptor	%
isolated/lonely	15	15.5%
awful	13	13.4%
horrific	12	12.4%
depressed, worst thing in life, hell	10	10.3%
horrendous	8	8.2%
rather be dead/suicidal, want no more children, wished for termination	7	7.2%
robbed of enjoyment of pregnancy	6	6.2%
debilitating, nightmare, hated it, hard/difficult	5	5.2%
terrible, trauma, horrible, hideous, caused PND/AND, put life on hold	4	4.1%
exhausting, felt like was dying, miserable	3	3.1%
emotional, soul destroying, anxious, devastating, angry, frightened, dreadful	2	2.1%
painful, grim, battle, mind altering, fate worse than death, torture, tedious, low, resentment, shock, vile, distressing, rough	1	1.0%

What would have improved things?

What would have improved things?	Number women reporting
HCP support	29
GP/midwife having more knowledge	24
emotional support	23
medication	21
information	12
awareness	11
earlier medication	9
links to hospital	3
day clinic	3
home IV	2

Emergent theme – it's all in your head

“I'm sad to say that all the nurses, midwives, doctors and consultants at my local hospital either didn't believe me, thought I was suffering **depression** which was causing my sickness, accused me of **not wanting the pregnancy** or just **ignored me** entirely.”

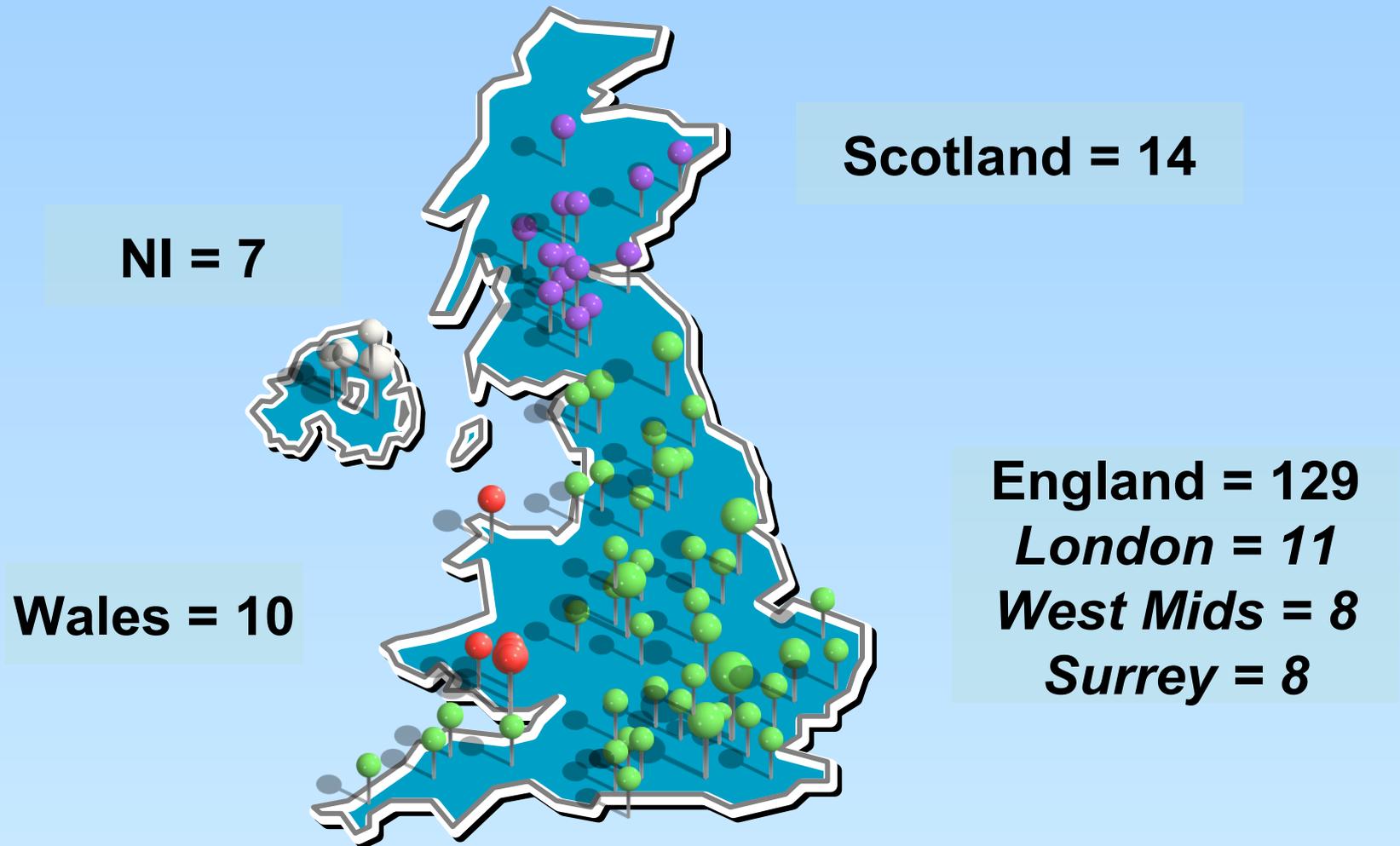
“...I carried on until I passed out then was accused of starving myself and being **anorexic** not wanting to gain weight.”

“Midwives - they were the worst in my experience very **judgemental** need more training on the condition it is not an **eating disorder**”

New Survey on Poor Attitudes to HG, Spring 2013

- Hosted on www.pregnancysicknesssos.co.uk
 - www.pregnancysicknesssos.co.uk – Surveys - Survey on Attitudes
- Advertised on
 - HG and PSS Facebook Group
 - Twitter @HGSupportUK (PSS twitter feed)
 - Mumsnet Hyperemesis support thread
- 163 Responses 12 April - 14th July (90% before 21st April)
 - Vast majority from HG and PSS facebook group
- Question
 - This survey is intended to record instances of comments which have been said to you by a healthcare professional which you felt have **trivialised** your illness. In particular we wish to record comments which have intimated that your illness is **all in your head**, or that you have **brought upon yourself** by your behaviour or attitude or comments which have suggested that an improvement in your mood would lead directly to an improvement in your symptoms. Only record instances said by a healthcare professional, not friends or family (unless they are also a GP or other HCP who would see pregnant women).

Poor Attitudes towards HG-UK distribution



Who made comment and when?

Responses in April - July 2013

Who made comment	Number	%
GP	58	35%
Midwife	41	20%
Hospital Doctor	32	25%
Hospital nurse	13	8%
Consultant	7	2%
Sonographer	3	4%
Pharmacist	3	2%
Healthcare Assistant	2	1%
Counsellor	1	1%
Hospital and GP staff	1	1%
Hospital HCP	1	1%
Nurse Practitioner	1	1%
Paramedic	1	1%
Total	164	

When was it said?	number	%
within past 6 months	39	24%
6 months to 1 year ago	19	12%
1 year to 18 months ago	34	21%
18 months to 2 years ago	15	9%
2 - 3 years ago	22	14%
3 - 4 years ago	9	6%
4 - 5 years ago	23	14%

Results at
www.pregnancysicknesssos.co.uk

Surveys
 Survey on Attitudes

Themes

- **Gingering and Cracking**

- *ofcourse [sic] you're sick love, you're pregnant. Try getting a dog or sucking on limes* GP, Bradford
- *'I give women like you a digestive biscuit and send them on there way cured* Midwife, Cheshire
- *I know the magic answer that will make you better - just keep some biscuits or crackers next to your bed and nibble on them when you wake up in the morning and you will feel fine* Hospital nurse Hertfordshire
- *sickness is part of pregnancy just try some ginger ale and dry biscuits* GP, Northern Ireland

Themes

- Psychosomatic

- *It can't be genuine morning sickness or HG because that only occurs in the first trimester of pregnancy. Your condition is psychological.* GP, Cheshire
- *During my third pregnancy my GP...ask the trainee doctor at the practice at the time to make diagnoses. The trainee quite openly said he thought I was anorexic.* GP, Wales
- *He said that talking to friends about how normal it is would make me feel better.* GP, Devon
- *Hyperemesis is a lot to do with mind over matter. You've had two ectopic pregnancies and now your mind is struggling to cope with the fact you have a strong, healthy intrauterine pregnancy this time.* Hospital Doctor, Cambridgeshire
- *Morning sickness is all in your head, so if you think you are going to be sick you will be.* GP Cumbria

Themes

- Pull Yourself together
 - *You really should make an effort to get put [sic] of bed and Not let us clear your vomit up* Hospital nurse, Kent
 - *Sometimes you just have to put up and shut up* Nurse Practitioner Lincolnshire
 - *You're pregnant of course you're sick just go home and deal with it* GP Hertfordshire
 - *That I needed to get out of bed & stop reching all the time* Hospital nurse, Northern Ireland
 - *Whilst laughing at me trying to explain the severity of my HG and the knock-on issues... "You're pregnant - deal with it* Consultant, Surrey
 - *if you dont pull yourself together you have a one way ticket to post partum depression* GP, Somerset

Themes

- Patient Heal Thyself

- *I overheard a midwife discussing me during an admission. She said I was making myself worse by choosing not to eat and that she felt sorry for my daughter since I was ruining her Christmas by choosing not to make myself better.* Midwife, County Durham
- *During second hospital admission - day 8 - "You just need to stop being sick to get better"* Hospital Doctor Norfolk
- *"If you try and stop yourself being sick you do realise you won't be sick anymore?!"*
Midwife, Kent
- *saw me unable to move of sofa picking at chips (one of my safe foods) said if I ate properly and didn't lay there feeling sorry for myself I would feel better.* Midwife Suffolk
- *'You shouldn't let yourself get so dehydrated so early in pregnancy'* GP Northern Ireland

Themes

- No Safe Drugs

- *As a GP I'm not [sic] allowed to prescribe Ondansatron'* GP Hampshire
- *Gp also said I will not give you drugs as it will harm your baby and it is all in your head!* GP Kent
- *Ondansatron can cause deformities in early pregnancy so we can't give it to you until at least 12 weeks* Hospital Doctor Hampshire
- *In the end he very begrudgingly prescribed Avomine, at a tiny dose (half a tablet very sparingly, basically said don't take it) and said there was nothing he could do because I was likely to need medication for at least 6 weeks which he wasn't prepared to give me. As a result of this appointment, I felt like a dreadful mother for considering taking medication, and like I was just really bad at being pregnant.* GP North Devon
- *went to collect my cyclizine prescription at 31 weeks and the pharmacist on handing me the meds said " I am not happy you taking these whilst pregnant, they are not safe"* Pharmacist London

Themes

- Evil Baby Poisoners

- *...the doctor asked why I was not eating or drinking because “did [I] know [I was] making [myself] worse” and was “harming the baby”. She questioned whether or not I wanted the baby to survive and accused me of doing it on purpose.*

Hospital Doctor Surrey

- *When I was unable to give a large urine sample due to dehydration from sickness I was accused of "intentional harming my child by refusing to take a simple test".*

Hospital doctor South Yorkshire

- *When I explained the hospital had prescribed them (ondansetron) originally and that I needed them his response was "so you're willing to risk your babies life to feel a bit less sick". ..he said he wasn't willing to do it [prescribe] as he was not prepared to deal with the consequences when I complained if there was something wrong with my baby.*

GP, West Midlands

- *When I asked him about anti-sickness drugs as I had read about them on the Internet, he looked at me like I was stupid and said 'have you never heard of thalidomide?' He implied that I was more concerned about my own well-being than the baby's and dismissed me from his office with out a backwards glance even though I was crying at that point through desperation*

GP West Dubartonshire

New Survey on Good Treatment for HG, Spring 2013

- Hosted on www.pregnancysicknesssos.co.uk
 - www.pregnancysicknesssos.co.uk – Surveys - Survey Good Practice
- Advertised on
 - HG and PSS Facebook Group
 - Twitter @HGSupportUK (PSS twitter feed)
 - Mumsnet Hyperemesis support thread
- 48 Responses 10 May - 21 May
 - All but one (Twitter) from HG and PSS facebook group
- Question
 - This survey is intended to gather information about **good to excellent care** for HG. Please tell us about healthcare professionals who you thought gave you good, very good or excellent treatment. Please fill in a **separate form for each person** who gave you this treatment eg if you saw two different GPs who were both good, please fill in a separate form for each one. The intention of the survey is to collect information about current practice so please only record instances **in the last 5 years**. This is for a UK based consultation, so please only submit a form if you had this care in **the UK** (including all countries in Great Britain and Northern Ireland).

Good Treatment of HG-UK distribution



NI = 0

Scotland = 4

Wales = 3

England = 40
Portsmouth = 4
Leicestershire = 3

Who made comment and when?

Responses in May 2013

Who gave good treatment	Number	%
GP	21	44%
Hospital consultant	8	17%
Hospital Midwife	3	6%
Community Midwife	2	4%
other hospital doctor eg registrar, SHO etc	7	15%
nurse practitioner	1	2%
A&E Nurse	1	2%
Hospital Consultant – Neurologist	1	2%
Nurse Practitioner	1	2%
PhD Midwifery	1	2%
Psychiatrist	1	2%
specialist midwife	1	2%
total	48	

When was it said?	number	%
within past 6 months	17	35%
6 months to 1 year ago	4	8%
1 year to 18 months ago	7	15%
18 months to 2 years ago	6	13%
2 - 3 years ago	3	6%
3 - 4 years ago	8	17%
4 - 5 years ago	3	6%

Results at
www.pregnancysicknesssos.co.uk
Surveys
Survey – Good Practice

Themes

Over and Above

- *Consultant gave me her work and home email, her secretary's phone number, her work number, her mobile, her home phone number, and the mobiles of her two registrars and told me to use them anytime of day or night, regardless of whether she was on shift or not* Consultant, Bradford
- *She was absolutely AMAZING!... She would come and see me on the ward as her shift was due to finish. I had access to her secretary and was allowed to bypass the normal procedures to be admitted and she would ring the ward immediately and secure a bed for me.* Consultant, Merseyside
- *Having trouble with meds and gp had told me nothing more could be done, midwife phoned on call registrar for me, visited me at home and arranged for new prescription. Community Midwife, Leicestershire*

Themes

Validation and Treatment

- *Always listened to my concerns, referred me to the correct specialists, willing to keep prescribing my Ondanstron throughout whole pregnancy.* GP Norfolk
- *Admitted for third time this consultant say [sic] down by my bed (most seemed to just stand there) and listened and wrote down my full history. Then immediately said it was time for ondanestron - I had been anticipating a massive fight for it and she just offered it, seemed to really care which meant a lot.* Consultant, Leicester
- *Instant understanding and help - his wife has had HG. Signed me off work.* GP, Cardiff
- *he also listened to my concerns and made sure blood tests were taken. Everyone else (apart from a nurse) just left me to it. He spent a lot of time at my bedside taking time to listen to me during my distress.* Other Hospital Doctor, Oldham

Sources of bias

- Respondents self selected
- Self reported and in some cases self diagnosed
- Respondents mostly recruited from mumsnet and Facebook HG forums, therefore may be those suffering more severely
- Some retrospective accounts – recall bias
- Need for prospective studies

Summary (1)

- Natural history of illness at odds with HCP perception
 - Rarely improves before 14 weeks
 - Almost never ceases before 14 weeks
 - Mean week of improvement 21 weeks
 - Symptoms persist till birth in majority (two thirds) of cases
 - Problem with definitions and use of word ‘remission’
- Low awareness amongst both HCPs and general public of
 - Reality of severity and suffering caused by HG
 - Proper treatment – too many willing to recommend ‘folkloric’ remedies
- Risk Factors:
 - Previous occurrence (68% recurrence)
 - Family history (35% close maternal relative)
 - Weak association with female foetus (59%)

Summary (2)

- Most effective medications, those who said they helped
 - Ondansetron 84%
 - Steroids 63% (but low numbers, only n = 8)
 - Cyclizine 61%
- Only alternative remedy which worked was rest
- Ginger effective for NO respondents
- Seabands effective for only 5%

Summary (3)

- **Experience with GPs patchy, ranging from excellent to very poor**
 - Only around 50% chance of having a positive experience of GP
 - < 50% admitted to hospital by GP
 - > 50% of GPs not effective at treating HG
 - Most common negative descriptor of GPs was 'not knowledgeable'
 - Only 5% of GPs gave referral to consultant
 - Widespread prevalence of HCPs who believe HG is psychogenic and trivialise illness
- **Women would like HCPs who**
 - Offer support
 - Listen
 - Prescribe medication
 - Are knowledgeable about HG

Recommendations (1)- what not to do...

- **stop advising ginger containing foodstuffs**
 - No evidence of efficacy, women report lack of effect
 - Only previous study in HG compares high dose capsules in in-patients, shows only marginal effect
- **stop advising that HG will resolve at 12 weeks,**
 - it will almost certainly last longer, treat HG as a chronic condition that may last for entire pregnancy
- **Don't imply that HG is psychosomatic**
 - Such evidence as has attempted to establish cause and effect indicates that HG causes mental health problems, not the other way round
 - Such implications are derogatory, insulting and lead to poor HCP-patient relations

Recommendations (2) – what to do...

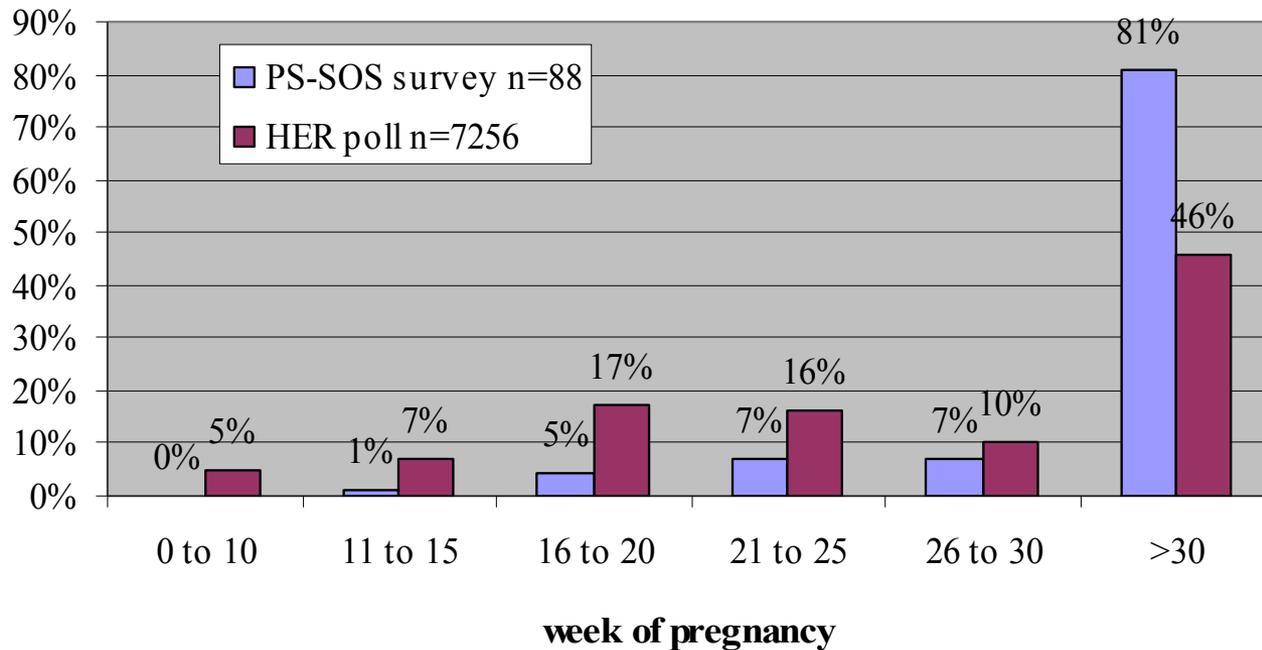
- **prescribe antiemetics**
- **advise rest and supply sick notes**
- **be sympathetic**
- **listen to patient**
- **believe what she tells you**

Acknowledgements

- Thanks to all respondents, especially the ones fighting the nausea to use the computer
- Thanks to fellow PSS volunteers for moral support

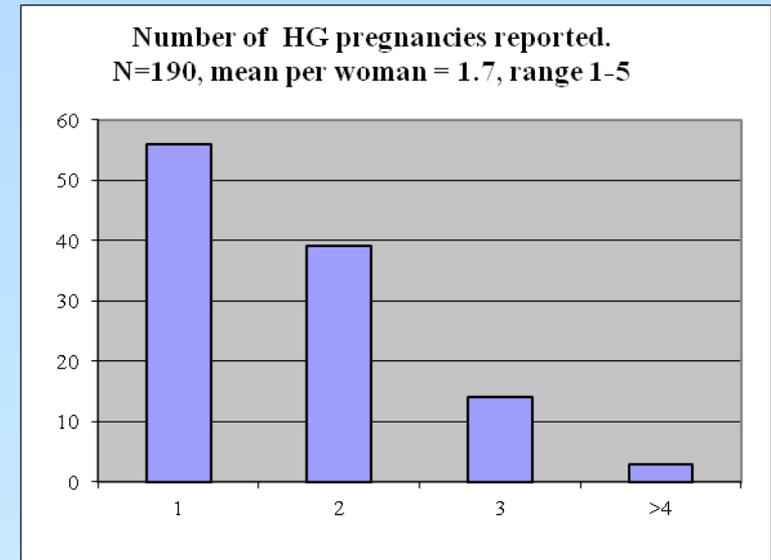
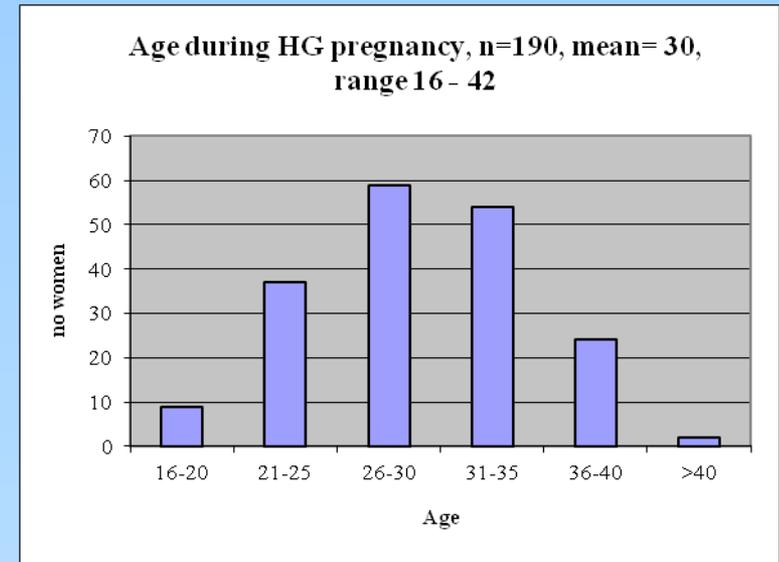
Compare with HER poll

**Comparison of HER poll with PS-SOS survey results.
Symptoms stopped at how many weeks**



Respondents' Characteristics

- respondents **n = 114**
- pregnant at time of responding **n = 63**
 - mean 19 weeks
 - range 5 – 40
- age during HG pregnancy
 - mean = **30 years**
 - range **16-42 years**
- Total pregnancies reported **n = 229**
 - HG pregnancies **n = 190**
 - Non-HG pregnancies **n = 39**
 - Miscarriages = **31** (17 women)
 - Terminations = **9** (6 women)
- HG pregnancies per woman
 - mean = **1.7**
 - range **1-5** (inc miscarriages, max 5 live births)
- Nation of Residence - **UK (98)**, The Netherlands (5), Norway (3), USA (3), Israel (2), Australia (1) and Malawi (1).



Have you used medication?

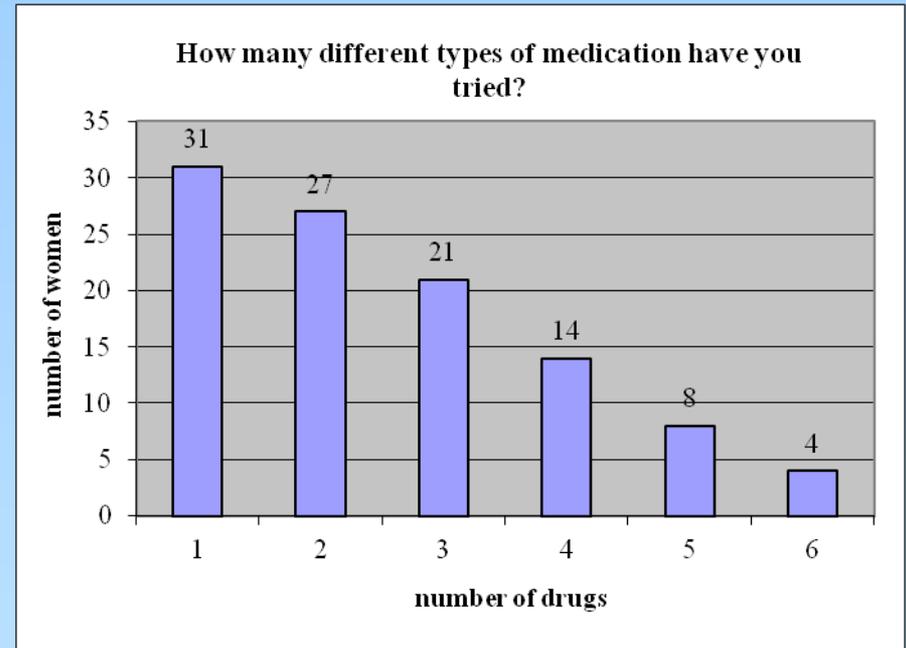
Yes – 94% (107) No 6% (7)

How many different types of medication have you tried?

mean 2.5
median 2,
mode 1
range 1 - 6

How many different types of medication were effective?

mean 1.8
median 1
mode 1
range 1 - 4

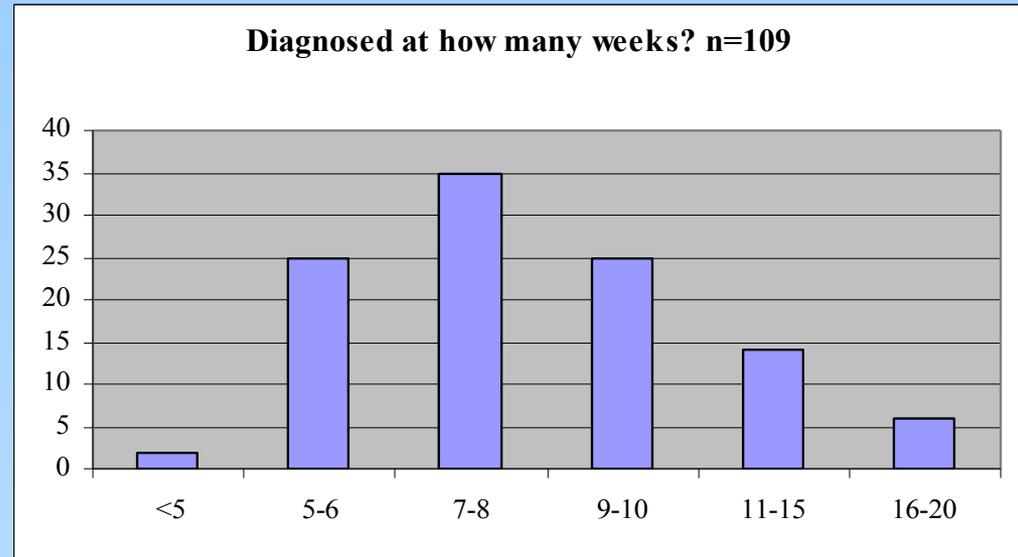


Diagnosed at how many weeks?

How many weeks pregnant when diagnosed?

mean **9 weeks**
range 3 – 38

*some women never received a diagnosis



How many weeks ill before diagnosis?

mean **4 weeks**
range 0.5 – 37

