

# Congenital cytomegalovirus infection, knowledge and attitudes among maternal health professionals and pregnant women

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## ORIGINAL

### Introduction

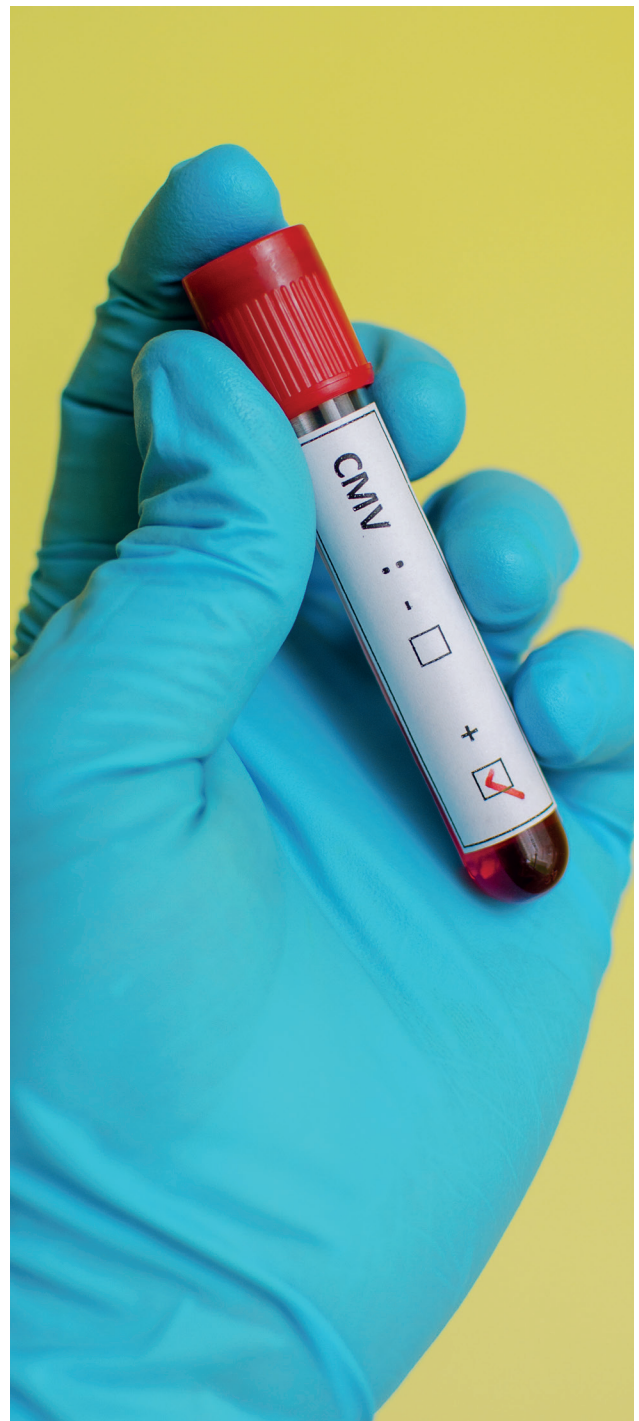
Congenital cytomegalovirus infection (CMV) is a leading cause of birth defects (Dollard *et al* 2007, Kenneson & Cannon 2007), yet anecdotal evidence suggests that the general public has a low awareness of the virus and health care professionals are unlikely to counsel pregnant women about the risks of infection. Taking simple hygiene measures during pregnancy could reduce instances of cytomegalovirus infection and lead to a reduction in birth defects, miscarriages and stillbirths.

This paper will present the results of two studies designed to assess knowledge of and attitudes towards CMV among maternal health professionals and pregnant women. The results demonstrate the need to increase knowledge about CMV infection among the general public and identify midwives as being well placed and willing to provide information on risk reduction to pregnant women.

We therefore recommend that information on risk reduction should be routinely made available to pregnant women in the UK and that midwives should be trained in how to deliver this information.

### Background

Cytomegalovirus is a common virus that belongs to the herpes virus family (NHS Choices 2014). It can be passed between people through contact with bodily fluids such as saliva and urine. In most cases, CMV does not cause symptoms in adults and children, although some people may experience mild flu-like symptoms. Many people come into contact with CMV during childhood and it is thought that up to 50–80% of adults in UK have been infected. As with other herpes viruses, once a person has been infected



with CMV, the virus stays inside their body for the rest of their life but, in most cases, it remains inactive and does not cause any problems. However, CMV infection does pose a risk to babies and pregnant women.

Pregnant women most commonly acquire CMV infection through exposure to the saliva and urine of young children, especially their own (Cannon & Davis 2005) and, in some women who had previously been infected with the virus, it can become reactivated. If a pregnant woman has CMV infection, it can be passed to the developing baby in her womb; this is known as congenital CMV and can lead to miscarriage, stillbirth or serious birth defects. Congenital CMV is a leading cause of birth defects (Cannon & Davis 2005): it accounts for up to 5% of cases of cerebral palsy and is the leading cause of non-genetic hearing loss. It is estimated that one or two babies in every 200 born in the UK, will carry congenital CMV. With an estimated birth prevalence of approximately 0.3–0.7% (Dollard *et al* 2007, Kenneson & Cannon 2007, Townsend *et al* 2011), congenital CMV is more common than Down's syndrome, spina bifida and cystic fibrosis.

Anecdotal evidence suggests that the general public has a low awareness of CMV and that health care professionals are unlikely to counsel pregnant women about the risks of CMV infection. Whilst CMV infection rates in pregnancy could be reduced through simple hygiene measures (Adler *et al* 2004, Cannon & Davis 2005), risk reduction is not routinely discussed in most countries. To date, there is no licensed vaccine to prevent CMV infection and there are no routine interventions for the treatment of antenatal CMV infection. However, the risk of acquiring infection may be reduced by avoiding contact with urine and saliva, particularly that of young children.

### Knowledge and attitudes among health care professionals and the public

Two independent surveys were developed to gather information on knowledge of and attitudes towards CMV infection during pregnancy. The first (CMV Action 2016) gathered information from antenatal health care professionals about their knowledge of CMV and other diseases, and measured knowledge of risk factors in pregnancy, CMV prevention and attitudes towards prevention. The second was a survey of over 1000 British women aged 18–44 (ComRes 2014), which gathered information from the general public to assess prior knowledge of CMV and attitudes towards self-care in pregnancy, what measures respondents would take to prevent CMV infection during pregnancy, and views on who should give advice and information to pregnant women.

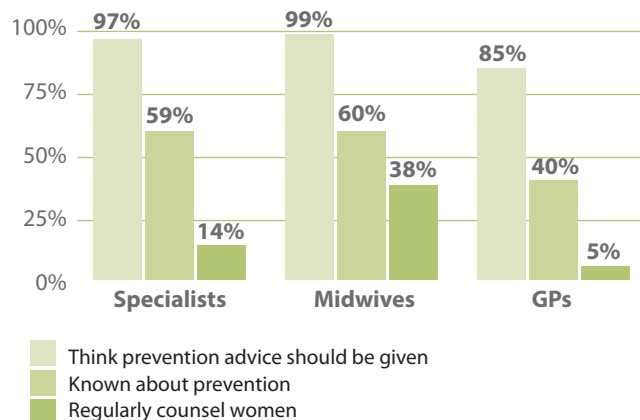
### Health care professionals' knowledge and attitudes

The professionals' survey used paper and online questionnaires to explore knowledge and concerns

of three groups of professionals in antenatal care: midwives, GPs and specialists in obstetrics, gynaecology and fetal medicine. Their prior knowledge of CMV was compared with that of Down's syndrome, rubella, toxoplasmosis and listeriosis (as risk factors in pregnancy) and their knowledge of prevention measures was explored. After being provided with basic information on CMV transmission, impact and risk reduction, they were asked about their attitudes towards CMV prevention and their views on barriers and enablers to CMV risk reduction.

All of the midwives responding to the survey believed that pregnant women should be given advice about reducing their risk of CMV infection and those midwives who knew about prevention methods reported that they did discuss risk reduction with pregnant women. However, whilst the vast majority of GPs and specialists surveyed agreed that pregnant women should be given advice about CMV prevention, 60% of GPs and 40% of specialists were not confident in their knowledge of the virus (Figure 1). They demonstrated a better factual knowledge of other common pregnancy issues and felt that midwives were best placed to provide advice and counselling to pregnant women on CMV.

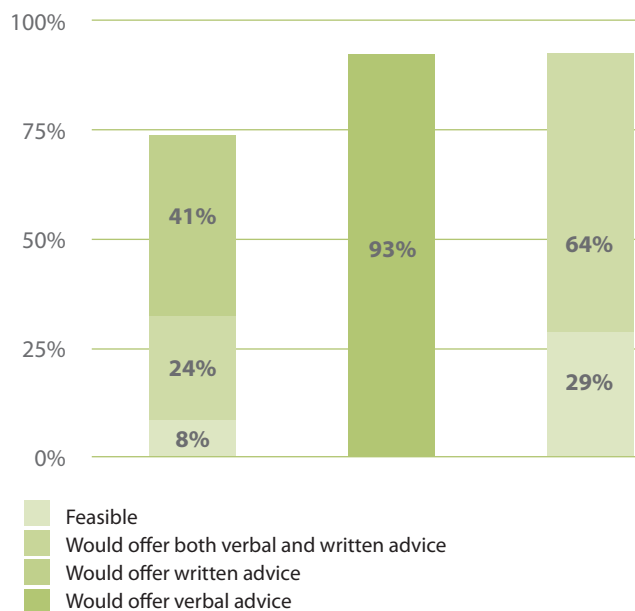
**Figure 1. Many of the professionals surveyed were not confident in their knowledge of CMV. However, motivation was high: more than 90% of professionals surveyed felt that pregnant women should be given advice about reducing risks of CMV infection**



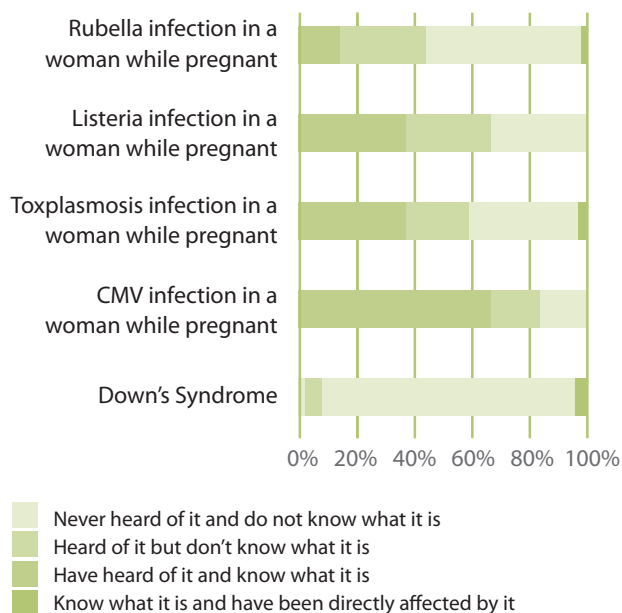
As illustrated in Figure 2, around 90% of professionals surveyed thought that advice on risk reduction should be given to pregnant women and that provision of such advice would be feasible subject to appropriate training. The results demonstrate a gap between professional willingness to discuss CMV risk reduction and the knowledge required to do so effectively. When midwives reported having heard of prevention measures, most also reported discussing risk reduction with pregnant women. Bridging the knowledge gap for midwives could therefore increase the provision of advice and information to pregnant women about CMV infection and prevention measures.

Less than one third of professionals surveyed anticipated issues in discussing CMV risk reduction, and the main barrier cited to the provision of information was lack of time. However, they also identified simple elements, such as training and information products that could help increase knowledge and overcome barriers.

**Figure 2. Most professionals surveyed thought it would be feasible to discuss prevention with pregnant women, given appropriate training**



**Figure 3. All respondents: how familiar are you with the following conditions?**



**Public knowledge and attitudes**

An online survey gathered information from a sample of UK adults to assess the level of knowledge of CMV infection and explore attitudes towards self-care in pregnancy. After answering an initial set of questions, respondents were shown information about CMV

infection and prevention and asked which measures they would be prepared to take in order to prevent infection in pregnancy. They were also asked how they would prefer to receive information on CMV during pregnancy.

As illustrated in Figure 3, a low number (approximately 14%) of respondents to the survey indicated prior knowledge of CMV; they showed a much greater awareness of the dangers of rubella, listeriosis and toxoplasmosis during pregnancy and of Down's syndrome. After reading the information on CMV, 91% of female respondents aged 18–44 agreed that pregnant women should be given information about preventing CMV infection during pregnancy and 75% agreed it was easy to prevent.

The majority of respondents reported that they would realistically take or encourage their partner to take a range of different preventative measures, including:

- washing hands with soap and water after coming into contact with bodily fluids
- avoiding sharing a child's dummy, cutlery, drinks or food
- avoiding kissing children on the mouth
- washing items that are contaminated with bodily fluids
- using condoms to guard against infection whilst pregnant.

All respondents favoured health care professionals rather than friends, family, partners or the internet as the best source of information for CMV.

**Recommendations and implications for practice**

The findings of the professionals' survey should be used to plan and implement a UK professional development strategy, for which key principles should include:

- targeting midwives as the highest priority
- aligning information with wider infection control and pregnancy topics
- designing training products to fit with professionals' limited time
- multichannel approaches
- a focus on the practicalities of how to discuss risk reduction and change behaviour among pregnant women.

Work has begun to develop a professional development strategy. So far, the following elements have been implemented: an e-learning module, a CMV training board game and a multidisciplinary study day on pregnancy infection. Other projects under development include an antenatal video, an e-learning case study, a CMV university module, and a broader programme of study and awareness days.

The patient survey demonstrates that there is a need and an appetite for knowledge about CMV among the general public. Furthermore, the messages tested in the survey had a notable impact on the intention

to engage in prevention behaviours. Not only is there a need to provide information on CMV infection to pregnant women but the survey results indicate that the messages tested are effective in changing attitudes towards the condition among British women aged 18–44.

In addition:

- There is a need to gather further evidence to define the relative importance of different prevention measures, and determine how best to present such measures to health care professionals and pregnant women. The messages should be incorporated into the information and advice already given to pregnant women.
- Training and support literature should be developed for health care professionals to address concerns about causing unnecessary anxiety in communicating risk reduction measures.
- Successful reduction of antenatal CMV infection requires partnership between clinicians, professional bodies, government agencies and educational institutions to find ways to meet the growing demand for information.

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