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‘Out of two bad choices, I took the slightly better one’: Vaccination dilemmas for Scottish and Polish migrant women during the H1N1 influenza pandemic

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SUMMARY

Objectives: Pregnancy has been identified as a risk factor for complications from pandemic H1N1 influenza, and pregnant women were identified as a target group for vaccination in the UK in the 2009 pandemic. Poland took a more conservative approach, and did not offer vaccination to pregnant women. Poland accounts for the largest wave of recent migrants to the UK, many of whom are in their reproductive years and continue to participate actively in Polish healthcare systems after migration. The authors speculated that different national responses may shape differences in approaches to the vaccine between Scottish and Polish women. This study therefore aimed to assess how pregnant Polish migrants to Scotland weighed up the risks and benefits of the vaccine for pandemic H1N1 influenza in comparison with their Scottish counterparts.

Study design: A qualitative interview-based study comparing the views of Scottish and Polish pregnant women on H1N1 vaccination was carried out in ‘real time’ during the first 2 weeks of the vaccination programme in November 2009.

Methods: One-to-one interviews were conducted with 10 women (five Polish and five Scottish) in their native language. Interviews were transcribed, translated, coded and analysed for differences and similarities in decision-making processes between the two groups.

Results: Contrary to expectations, Scottish and Polish women drew on a strikingly similar set of considerations in deciding whether or not to accept the vaccine, with individual women reaching different conclusions. Almost all of the women adopted a critical stance towards the vaccine. While most women understood that pregnancy was a risk factor for complications from influenza, their primary concern was protecting family health overall and their fetus in particular. Deciding whether or not to accept the vaccine was difficult for women. Some identified a contradiction between the culture of caution which characterizes pregnancy-related advice, and the fact that they were being urged to accept what was perceived as a relatively untested vaccine. Their health histories, individual constitutions, and whether their everyday routines exposed them to sources of infection combined to establish their perceived ‘candidacy’ for contracting infection. Neither Scottish nor Polish women felt that ‘official’ information addressed their concerns in sufficient detail, and almost all of the women sought information from a variety of sources. Polish women found it more difficult to access information and advice from the National Health Service than

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their Scottish counterparts. For most respondents, deciding whether or not to accept the vaccine was an attenuated process, culminating for many in choosing the 'least worst' option in the context of competing risks.

Conclusions: To the authors' knowledge, this is the first study to assess perceptions of H1N1 immunization risk in pregnant women in 'real time'. It highlights the important unmet needs for information that women need to be able to make informed vaccination choices, and the challenges of producing such information in a context of uncertainty. This is of particular relevance as many countries, including the UK, are actively reviewing their plans for vaccination programmes during pregnancy.

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Introduction

In April 2009, the emergence of H1N1, the first influenza pandemic in over 30 years, prompted the rapid development of a national vaccination programme in the UK, initiated in October 2009. This aimed to protect priority groups such as health workers and those identified as being at greatest risk of complications from the infection, including those with long-term health conditions and pregnant women. The vaccine used had been licensed on the basis of clinical trials of serological immunity,¹ but was not accompanied by data on clinical outcomes. The speed with which the vaccination programme developed in the face of the pandemic allowed little scope for assessing its acceptability amongst target groups.

Existing research findings on vaccine decision-making focus primarily on acceptability and risk in relation to childhood routine immunizations, particularly those such as measles, mumps, rubella (MMR) which have been the focus of 'vaccine anxieties',^{2,3} and, more recently, human papillomavirus (HPV) vaccine.^{4,5} The small volume of qualitative research on influenza vaccines prior to the H1N1 pandemic focused primarily on older people, previously a prime target for influenza vaccination programmes.⁶ Qualitative research following the pandemic has explored media representations,⁷ public views of media and government responses,⁸ and perceptions of novel vaccines.⁹ Although pregnant women have been included in more general studies,⁸ no qualitative studies focusing on this group have been published previously.

This is particularly pertinent because pregnant women in the UK are not currently offered routine vaccination against infectious diseases. On the contrary, a number of vaccines (although not the seasonal influenza vaccine) are contraindicated in pregnancy. In this context, very little is currently known about how women weigh up the risks and benefits of vaccination for themselves and their fetus. This is an important area for investigation as the UK and other countries are actively reviewing their plans for vaccination programmes during pregnancy in the wake of the H1N1 pandemic.

Some countries adopted a more conservative approach to vaccination than the UK, opting to embark on mass vaccination of target groups only when further information on clinical endpoints were available.¹⁰ Amongst these countries was Poland, which opted not to invest funding in purchasing the vaccine for its population in the absence of data on the probable scale of H1N1 infection.¹¹ Following expansion of the European Union in 2004, Poland accounts for the greatest

proportion of recent migrants to the UK, a high proportion of whom are of reproductive age, and continue to maintain strong links with Poland.^{12,13} Recently completed qualitative research in Lothian, Scotland suggests that Polish women actively participate in both UK and Polish systems of antenatal care, and that expectations derived from Poland form the basis for their evaluation of care received in Scotland.¹⁴ Given this pattern, the authors speculated that the conservative approach towards the vaccine on the part of the Polish Government had the potential to shape a more critical stance towards the vaccine in Polish migrants than Scottish women.

The authors therefore undertook a small study to explore this through comparing the 'real time' decision-making processes about H1N1 vaccination in a small sample of pregnant recent migrants from Poland with an equivalent sample of Scottish women in Lothian. Lothian has a population of approximately 824,000 living in and around the Edinburgh area. It is home to around one in three Polish migrants to Scotland, and approximately 30,000 Poles have settled in Lothian since 2004, with 5% of births in the region being to mothers born in Poland.^{15,16}

Methods

Ten women (five Polish, five Scottish) were recruited to the study during the first 2 weeks of the vaccination programme in November 2009. Details are provided in Table 1. Participants, who ranged between 18 and 40 weeks of gestation, were recruited from routine antenatal settings in Lothian. Polish women were recruited through a parenthood education session conducted in Polish. The bilingual researcher outlined the aims of the research during the session, collected the details of interested women, and contacted them to arrange an interview. Women were interviewed at their nearest hospital. Scottish women were recruited while waiting for antenatal and ultrasound scan appointments, and all women who agreed to participate opted to be interviewed immediately following these appointments. Letters of invitation, information sheets and consent forms for participation in the research were provided in the women's native language, and signed consent was taken from all participants prior to interview.

Details were collected of women's current or most recent employment. Socio-economic classification was allocated using the simplified National Statistics Socio-economic

Table 1 – Respondent characteristics.

Inter-viewee	Age band (years)	Vaccine	Socio-economic status	Highest educational qualification	First-time mother	Gestation (months)
S1	30–34	N	3	Vocational qualification	N	8
S2	30–34	Y	1	Higher degree	N	8
S3	20–24	Planning	3	Vocational qualification	N	7
S4	20–24	N	2	Undergraduate degree	Y	4
S5	30–34	Y	1	Higher degree	Y	4
P1	30–34	Y	3	N/K	N	6
P2	20–24	Y	3	Vocational qualification	N	9
P3	30–34	N	2	Higher degree	N	8
P4	25–29	N	3	Vocational qualification	Y	7
P5	25–29	N	3	Undergraduate degree	Y	7

N/K, not known.

In the N-SEC classification, 1 represents managerial and professional occupations, 2 represents intermediate occupations, and 3 represents routine and manual occupations.¹⁷

Classification (NS-SEC).¹⁷ Details of women's highest educational qualification were also collected. NS-SEC may not relate to educational qualifications in the context of migration, where jobs commensurate with Polish qualifications may be difficult to obtain.^{18,19} The profile of educational qualifications between the Polish and Scottish samples was broadly equivalent, but the occupational profile was not. While two women in the Scottish sample had most recently worked in a routine or manual occupation, four of their Polish counterparts fell into this category, and none were occupied in occupations which reflected their qualifications.

Data were collected through semi-structured interviews. These elicited information about women's socio-economic backgrounds, migration histories, family circumstances, general health during their current pregnancy, and views of the health care they received during pregnancy. Women were asked about their perceptions and experience of H1N1 influenza and the vaccine. They were prompted to discuss their sources of information about these. Both Scottish and Polish women were asked for their views about government responses to the pandemic in order to encourage comparison between the UK and elsewhere. Finally, the women were asked how they made decisions about whether or not to accept the vaccine, and who they involved in their decision. Unanticipated issues arising from interviews were incorporated as questions and prompts into interviews with subsequent respondents in order to check them for wider resonance. For example, several earlier respondents raised the MMR controversy as relevant to their decision-making, and this was included as a prompt in interviews with subsequent respondents.

Interviews were conducted by a bilingual female doctor (AAU) and were recorded. AAU transcribed Polish transcripts and translated them into English, and English language interviews were transcribed professionally. Transcripts were reviewed by all members of the research team, and analysed both deductively and inductively. Driven by the initial research question, transcripts were scrutinized for and coded by differences and similarities between the Polish and Scottish groups. They were also coded by general themes arising from the data, which were refined after discussion into the four 'higher order' themes – protecting children's health, risk

and trust in relation to the pandemic and vaccine, 'candidacy' for infection, and information and decision-making – which structure this paper. Coding was supported by the NVivo 6 qualitative data analysis software. Data were analysed to account for the full range of perspectives represented, and were actively scrutinized for 'deviant cases' which potentially contradicted emerging analytic conclusions.²⁰

Results

All those interviewed, with the exception of one Polish woman, adopted a critical stance towards the H1N1 vaccine, and three of the five Scottish women also expressed some scepticism about the scale and seriousness of the H1N1 pandemic. The fact that the Polish Government had taken a different stance on the vaccine to the UK Government had little influence on Polish women's decision-making. Rather, Scottish and Polish women drew on a strikingly similar set of considerations as they weighed up the risks and benefits of accepting what most perceived as a relatively untested vaccine in pregnancy against the risk of infection.

Firstly, they considered risks to their own health in the wider context of family health, and most considered themselves less vulnerable, either to infection or to potential side-effects of the vaccine, than their unborn or young children. Secondly, they drew on highly personalized lay epidemiology and immunology in assessing their 'candidacy' for infection. Finally, their decisions were informed by their degree of trust in 'official' information about the safety of the vaccine, sometimes drawing on earlier 'vaccine scares'. Individual women reached different conclusions about whether or not to accept the vaccine on the basis of these considerations, but decision-making was difficult and anxiety-provoking for all women.

Protecting children's health

The publicity accompanying the roll-out of the vaccination programme to pregnant women focused on the specific vulnerability of pregnant women to complications from H1N1 influenza. However, although most women clearly

understood this, they perceived themselves as being far less vulnerable than their unborn children. For all women interviewed, their fetus was the primary concern in weighing up the risks and benefits of being vaccinated. The protective effect of the vaccine on the fetus was a key motivation for those women positively disposed towards vaccination, both to protect the baby *in utero* and from infection once it had been born. Conversely, some non-vaccinators perceived the vaccine to be purely for their own benefit, offering no protection for the fetus. The fetus was an equal concern for those concerned that the vaccine may have side-effects:

“What I wanted to find out whether there were any tests conducted on [the vaccine], that it will not harm my baby.... I’m not important, the most important thing is about my baby.” (P4, non-vaccinator)

Women also considered the threat posed by influenza or vaccination to their family as a whole, rather than simply to themselves and their unborn children. Those who were not first-time mothers felt uncomfortable being prioritized for vaccination above their young children. As one woman, referring to her young child, commented:

“If anybody’s going to get it, it will be him and he’s kind of just so little.” (S2, vaccine acceptor)

The vulnerability of children was particularly acute for Polish women, several of whom highlighted the deaths of children reported in the Polish press. More pragmatically, some women were concerned that their existing children, if unvaccinated, may be a vector for exposing newborns to infection. For several others, the risk of being judged by others as a ‘bad mother’ for whichever course of action they took heightened the anxiety surrounding decision-making.

‘Candidacy’ and lay epidemiology

The concept of ‘candidacy’ was developed in sociological explorations of lay understandings of the factors that rendered individuals at risk of coronary heart disease²¹ and cancers.²² However, it has been little used in relation to lay understandings of infectious diseases. The concept of candidacy encapsulates perspectives on the ‘personal characteristics and lifestyle that make some people more or less likely to succumb to a disease’.²² It proved useful for analysing how women drew on their own personalized understanding of infection and immunity to assess themselves or members of their family as potential ‘candidates’ for H1N1 infection, which in turn informed their decisions about whether or not to accept the vaccine.

Busy places such as shopping centres, buses and schools were perceived as potential reservoirs of infection, and the extent to which women encountered such places in the course of their daily lives bore on how they assessed their ‘candidacy’. Changing circumstances could alter perceptions of risk, as one woman highlighted:

“I didn’t feel at that high risk to be honest. I sit in an office of four people and I go home to my house in the country ... I think I’m

fine. But she [midwife] pointed out that we were going on a long haul flight... and you know the risk there could increase and I agreed with that which is why I then got it done.” (S5, vaccine acceptor)

In the view of some women, season, and particularly the fact that they were pregnant during the winter, rendered them more vulnerable to infection, reflecting the continuing salience of season in lay assessment of vulnerability to illness.²³ Women’s perceptions of their individual constitutions and health histories (e.g. whether they were ‘prone’ to influenza) also contributed to their assessment of their candidacy.

The lay reasoning that women drew on clearly reflected themes in ‘official’ epidemiology and information about the pandemic. For example, there was reference across most interviews to the fact that underlying medical conditions and pregnancy could intersect with immunity to render some individuals particularly vulnerable to complications from influenza. There was little evidence to suggest that those who refused the vaccine did so because they had failed to understand official messages about the pandemic or vaccination programme.

Risk and trust in relation to the pandemic and vaccine

The over-riding concern for most women in decision-making was their assessment about the safety of the vaccine. Although a number of women had a relatively sophisticated recognition of the fact that the vaccine was made up of elements which had been well tested in combination with ‘new’ elements, hesitancy or suspicion about the vaccine was a consistent thread across all interviews. These centred on the speed with which it had been developed, and what was perceived to be the resulting lack of evidence about its long-term efficacy or side-effects for women and, more importantly, fetuses. These anxieties, sometimes drawing on the vaccine scares surrounding the MMR and (to a lesser extent) human papillomavirus vaccines,^{2,24} characterized most women’s accounts of decision-making:

“Diseases are worse than the system reacting to the vaccine but after having read the consequences following the vaccine MMR, I think that this [flu] vaccine may have parts of certain metals, I don’t know, this is very difficult.” (P3, non-vaccinator)

Several women expressed their concern about being in a cohort of ‘guinea pigs’ for the vaccine. For them, accepting the vaccine would have been more straightforward had results from an earlier cohort been available and the range of their concerns addressed. One woman summed up her extensive range of concerns, highlighting how these had not been tackled in the information she had received from the National Health Service (NHS):

“... the sheet that they gave me didn’t actually give me much information on the vaccination ... it was all based on other vaccines, there was nothing to say what the side-effects were for this vaccine... They don’t want babies under 6 months to be vaccinated ...but they’re quite happy to vaccinate me which is

going to go straight into baby anyway ... and have they used it enough to find out that it's going to do the job that they want it to do? I think it would make it easier if it was true information, stating that it was for this strain of flu and this is what's happened to people that have had it and people that haven't had it." (S1, non-vaccinator)

More generally, several women identified contradictions between the increasing caution urged in both popular and medical circles about the dangers of harming the fetus through drinking, smoking or eating the wrong types of foods with the fact that they were now being asked to accept what was perceived as an untried and untested vaccine. This was exacerbated where women had been informed that other vaccines were contra-indicated in pregnancy:

"...and then suddenly they want to vaccinate you against something which we've only heard about in the news or the press for you know approximately a year or less and I think ... 'well, if you won't give me a vaccine for Hep A that you've known about for ... hundreds of years, why will you suddenly give me a vaccine for swine flu?'" (S5, vaccine acceptor)

Interestingly, however, despite the unease surrounding the UK vaccination programme, the more cautious response to recommending the vaccine to pregnant women in Poland was not positively endorsed by any of the Polish respondents. All but one of the five Polish respondents were critical of the Polish Government's response on the basis that they were unprepared for the potential consequences of the pandemic:

"Poland is standing on the side lines and observing, and they are dragging their feet and it does not even know yet whether to vaccinate or not... (P5, non-vaccinator)"

While both sets of women endorsed the UK Government's attempts at containing the pandemic through vaccination, this did not necessarily relate to their personal decisions about whether or not to accept it.

Information and decision-making

Furthermore, the fact that the vaccine was 'officially' endorsed did not mean that it was trusted. Women's scepticism was reflected in the fact that they did not accord particular privilege to 'official' information emanating from the Scottish Government and NHS over other sources of information. Most Scottish women reported discussing the infection and the vaccine with their midwives as one source amongst a range of others. Four women (two Scottish and two Polish women) perceived official information to be a form of 'propaganda'. They attempted to get 'behind' the advice they felt health professionals were instructed to provide, which women perceived as not necessarily coincident with professionals' own personal opinions on the vaccine.

All women were proactive, to a greater or lesser degree, in seeking out alternative information and opinions about the vaccine, predominantly through their social networks and the Internet. Polish women, in particular, described the Internet as a valuable source of information. This may be related to the

fact that they found it more difficult than their Scottish counterparts to access NHS advice in the form of published or online information, or face-to-face discussion with professionals. This formed one of the most significant differences between the experiences of Scottish and Polish women. Polish women described time-consuming efforts at translating information on websites using online tools, and carefully preparing for in-depth discussions with health professionals:

"I took a leaflet, from the surgery that is in English, which I translated on Google into Polish so that I would know what they are talking about.... Everyone is giving it out... So I translated it into Polish. And this lady [the receptionist] did say that she would phone. I even translated a few words so that I knew what to talk about but she never phoned, so I didn't go to my appointment." (P5, non-vaccinator)

There was a widespread sense that information emanating from official sources did not address women's predominant and detailed concerns about the pandemic, or the side-effects of the vaccine. Lack of information about effects on the fetus emerged as the most significant gap. Indeed, the section in the NHS Health Scotland leaflets on H1N1 vaccine headed 'Is the vaccine safe for me and my baby?' focuses primarily on the pregnant woman to the exclusion of the fetus.²⁵ Conflicting information across the different sources of advice consulted by women further exacerbated what was generally construed to be a difficult decision about whether or not to accept the vaccine. In light of this, a number of women, both Polish and Scottish, identified a 'personal expert'. This was usually someone who bridged the medical sphere and their personal networks:

"I have a very close friend, and her mother is a doctor, and her dad also, and I eventually phoned her because for me it is so difficult ... I really don't know what I should do, she then phoned her mum and advised me. Well we decided.. she decided that I should not take this vaccine." (P5, non-vaccinator)

Decision-making was surrounded with anxiety for all women, and was often an attenuated and fluctuating process of weighing up different sources of information in the light of their experience. Those who had accepted the vaccine described it in terms of a 'leap of faith', reassuring themselves that the Government would not risk 'the wrath of God', in the words of one woman, by encouraging pregnant women to accept an unsafe vaccine. For most, their decision constituted the 'least worst' option in the context of a difficult set of choices, and anxiety could continue even after a decision had been made:

"I am still not sure whether I took the right decision, I keep thinking did I do the right thing? But I think out of two bad choices, I took the slightly better one....maybe a slightly smaller risk." (P1, vaccine acceptor)

Discussion

This study aimed to explore whether Polish women may be more critical towards the H1N1 vaccine than their Scottish

counterparts, given the more conservative approach to promoting the vaccine adopted by the Polish Government. This was not borne out. Rather, Poland's conservatism was seen to signal a lack of preparedness which reflected badly on the Polish Government. Overall, Polish and Scottish women drew on a strikingly similar set of considerations in deciding whether or not to accept the vaccine.

This study is limited by the small numbers involved, and the fact that the imperative dictated by recruiting women within a short time-scale meant that the authors were unable to sample purposively for characteristics such as educational attainment, which have a potential bearing on health decision-making. However, the profiles of the Polish and Scottish samples were broadly similar with respect to age, occupation and educational attainment. The strengths of the study lie in its provision of in-depth, cross-cultural data generated in 'real time' at the point when the vaccine was introduced, rather than retrospective accounts. These findings are particularly relevant as the UK and other countries are actively reviewing their plans for influenza vaccination programmes during pregnancy.

Accounts of both Polish and Scottish women were marked by references to what sociologists term a 'risk society', where risks multiply as life modernizes, but where 'scientific' responses to old or new risks – in the form of infectious diseases, nuclear energy or intensive farming, for example – are perceived to carry their own, often overwhelming, risks.^{26, 27} In this case, the risk posed by the global circulation of the H1N1 infection was countered by a solution in the form of a vaccine which was perceived to be potentially risky for three main reasons. Firstly, the speed with which the vaccine was developed engendered a lack of trust in its safety, which reflects findings elsewhere.⁸ Secondly, women were concerned about the potential effects of the vaccine on the unborn child. This came for many in the wake of the MMR controversy, which has been at the forefront of debates about vaccination risk in the public sphere. The present findings are consistent with others that the MMR controversy may influence not only MMR itself but vaccine decision-making more generally.²⁸ Finally, women identified a general contradiction between what they perceived as an insufficiently tested vaccine and the culture of hypercaution surrounding pregnancy.

Refusal of the vaccine was linked to how women weighed up these concerns in the wider context of a personalized lay epidemiology. This consisted of readings of risk and vulnerability to do with season, work, women's individual constitutions and their children's susceptibility to infection. Refusal of the vaccine was not linked significantly to lack of knowledge of the risks that H1N1 posed to women in pregnancy. This suggests little evidence, in this case, to support the 'deficit model' of lay understanding of science. This is where lay concerns are assumed to arise from misunderstanding the rationale and science underlying medical or public health interventions.²⁹ Here, by contrast, women's personalized concerns were deployed for almost all respondents alongside a measure of evident scientific literacy. The long history of robust clinical trials is harnessed prominently in material on MMR and other related areas, such as the licensing of new medicines, in order to reassure the public of their safety. It was exactly this type of scientific reasoning that women drew

on in highlighting what they perceived as the absence of such information on the H1N1 vaccine, and their consequent uncertainty about whether or not to accept it.

The fact that neither the absence of robust data nor the wider set of concerns voiced by both sets of women were addressed in 'official' sources of information about the pandemic and vaccine engendered a lack of trust in this material. Interestingly, advice from individuals with a medical perspective was not necessarily regarded with similar scepticism. This is evident in the fact that many women actively sought out 'personal experts' who were able to marry their medical expertise with an understanding of women's personal worlds; and respondents' attempts to access what health professionals 'really thought' rather than what they had been told to say.

This raises the wider question of how to tackle uncertainty in the provision of published and face-to-face health information for the public. Rolling out the H1N1 vaccine quickly in response to the pandemic was a particularly challenging public health initiative in this respect. The importance of providing information which is clearly written and accessible to those with a range of literacy abilities is now well recognized in the UK.³⁰ Doing so in a way that addresses lay concerns, acknowledges areas of scientific or medical uncertainty, and heeds the sophistication of its audiences (including those whose literacy levels are low) is challenging.³¹ Although this was a small sample, those with lower educational qualifications were no less questioning of official sources of information than their counterparts with higher degrees. Explicitly addressing uncertainty and acknowledging areas where there has been no opportunity to accumulate evidence may serve to enhance rather than diminish the credibility of face-to-face or published material. Refining and evaluating material which enables informed choice as the influenza vaccine is offered routinely to pregnant women in the UK provides a potential opportunity to address these wider and challenging issues in the development of health information.

Finally, although there were striking similarities between Polish and Scottish women in their considerations about vaccination, Polish women were clearly disadvantaged in accessing both published and face-to-face information and advice about the pandemic and vaccine. The study findings suggest that non-English speakers may need clearer signposting to translated sources, and help accessing face-to-face advice. This is likely to shape access to information for other migrant and non-English-speaking groups. The fact that processes of migration did not have a significant influence on approaches to the H1N1 vaccine in this small study obviously cannot be taken to hold across the increasingly heterogeneous groups making up the UK population. It remains crucial to include ethnically varied samples in research about vaccine acceptability and development of information.

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Ethical approval

The study was submitted to the South East Scotland Ethics Service and was not considered to require ethical review. The study was carried out in line with the British Sociological Association's guidelines for ethical practice.³² Approval was obtained for appropriate use of data from the Caldicott Guardian.

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Competing interests

None declared.

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