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**Bringing to Life Patient Experiences in
Prematurity Survey
2014
Ireland**

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Section 1

Programming

Method

- Online survey with the cooperation of Irish Neonatal Health Alliance (INHA) and euopinions.ie consumer panel
- Sample achieved is 152.
- Euopinions: 110
- INHA: 42

Fieldwork

- August and September 2014.
- Region: Ireland

Respondents

- Females and males where last baby was born within last 2 years or are expecting a baby.

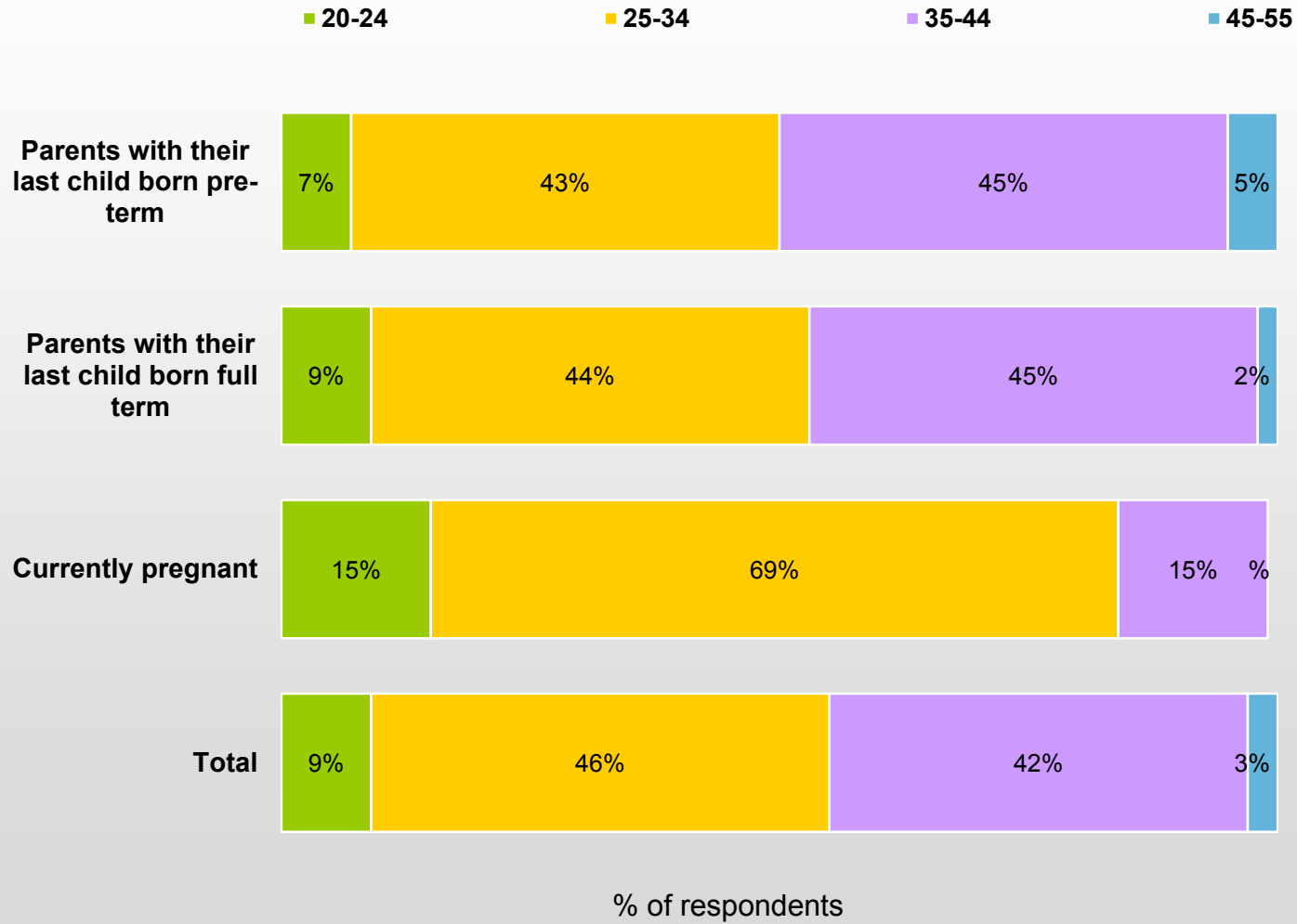
Groupings

- Parents with their last child born pre-term,
- Parents with their last child born full-term,
- Those currently pregnant.

Warning!

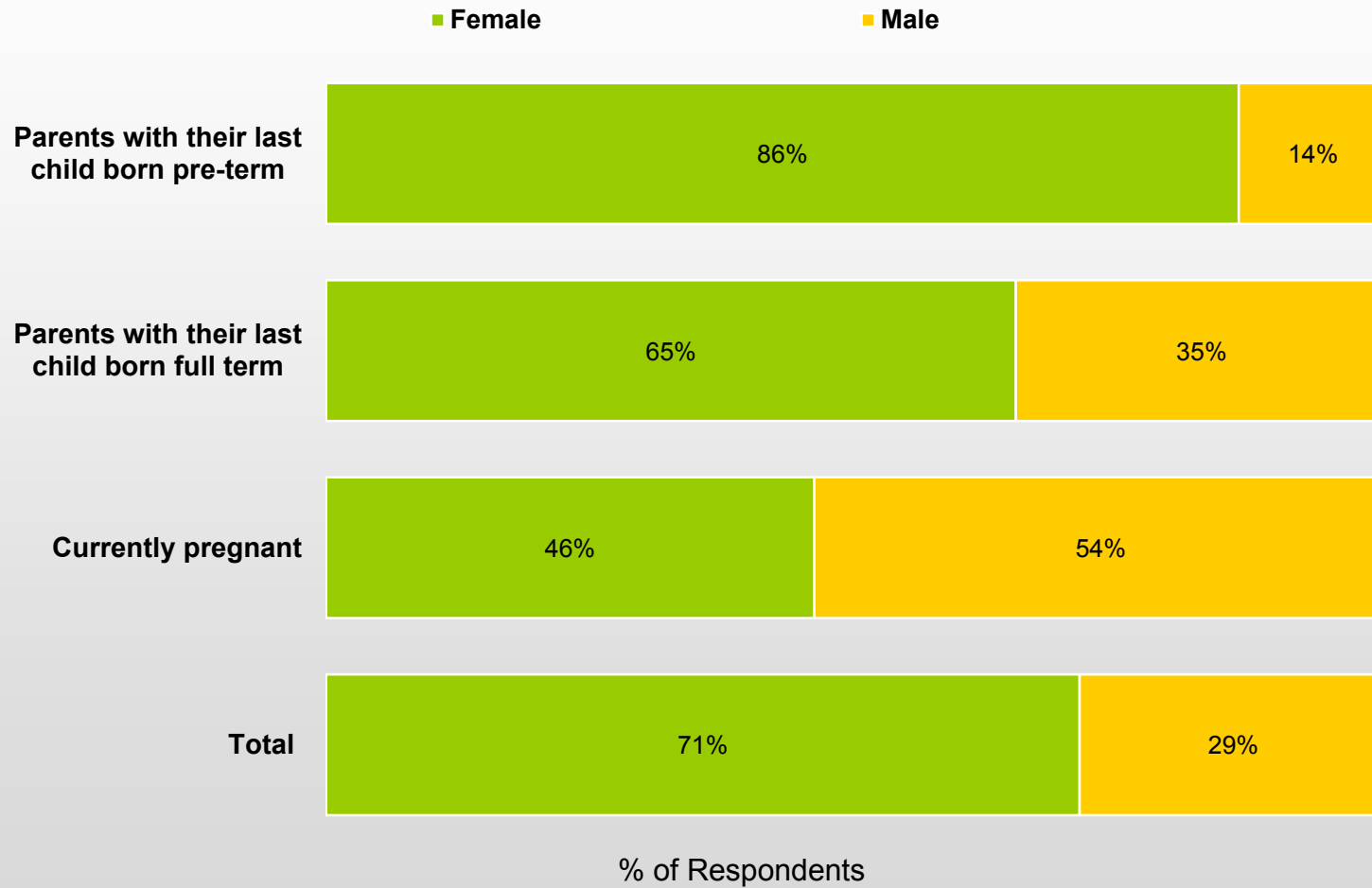
- **Some base sizes are very small!**
- **Be Careful!**

Indication of Age



Base: 152 respondents
 Q1. Please indicate your age:

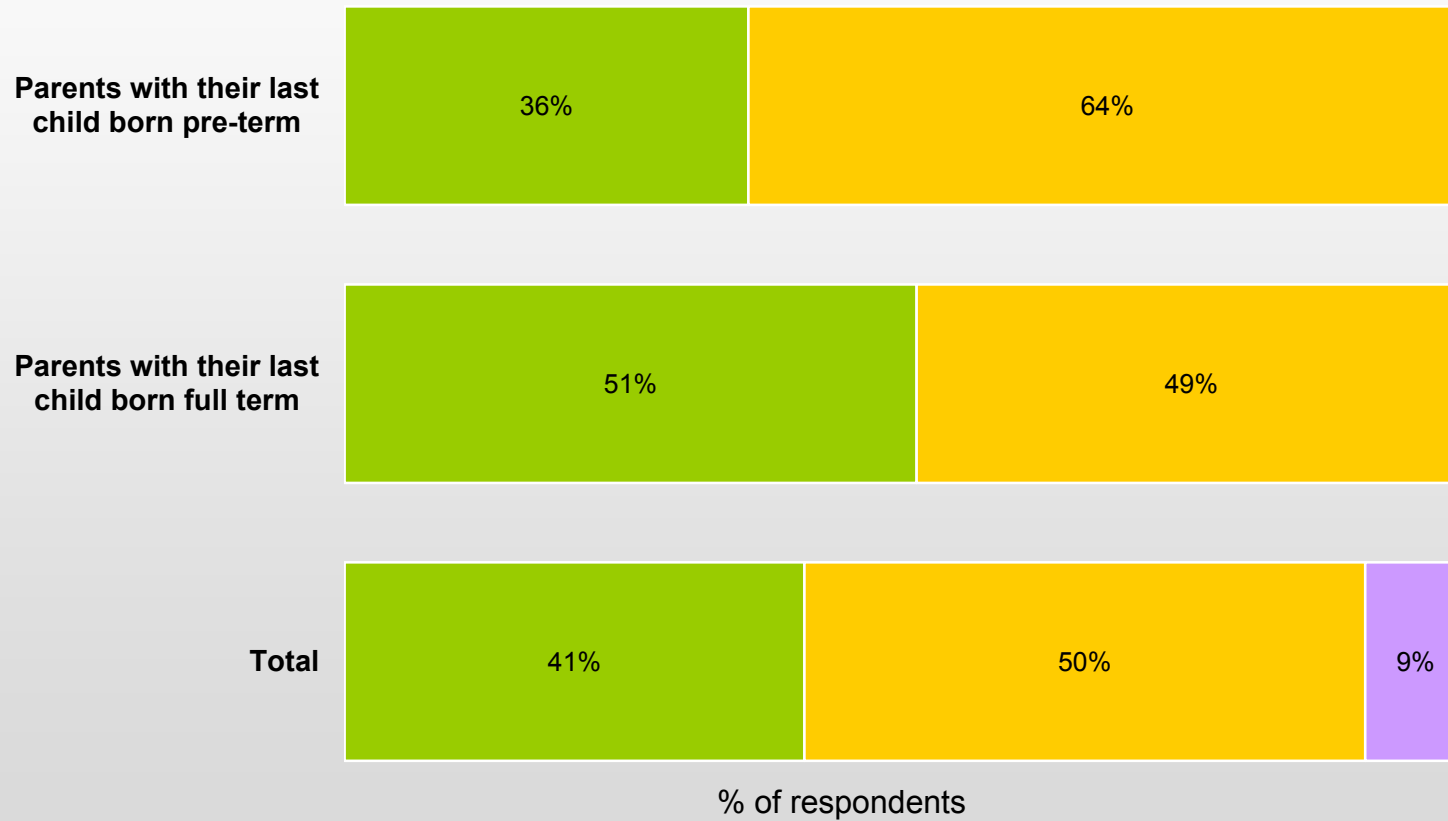
Gender



Base: 151
Q 2. Please indicate your gender:

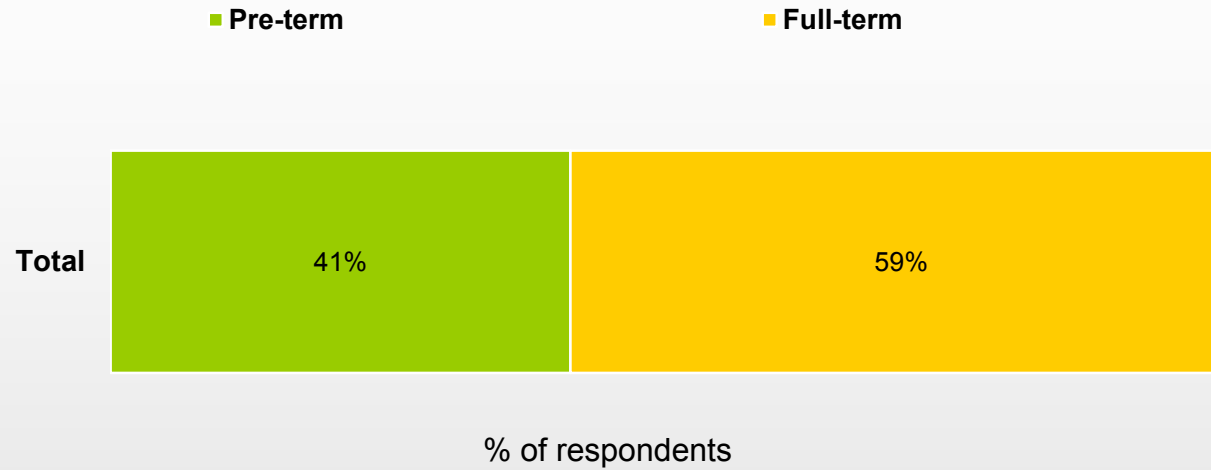
When was the last baby born

■ Within the past 12 months ■ 1 to 2 years ago ■ Currently pregnant



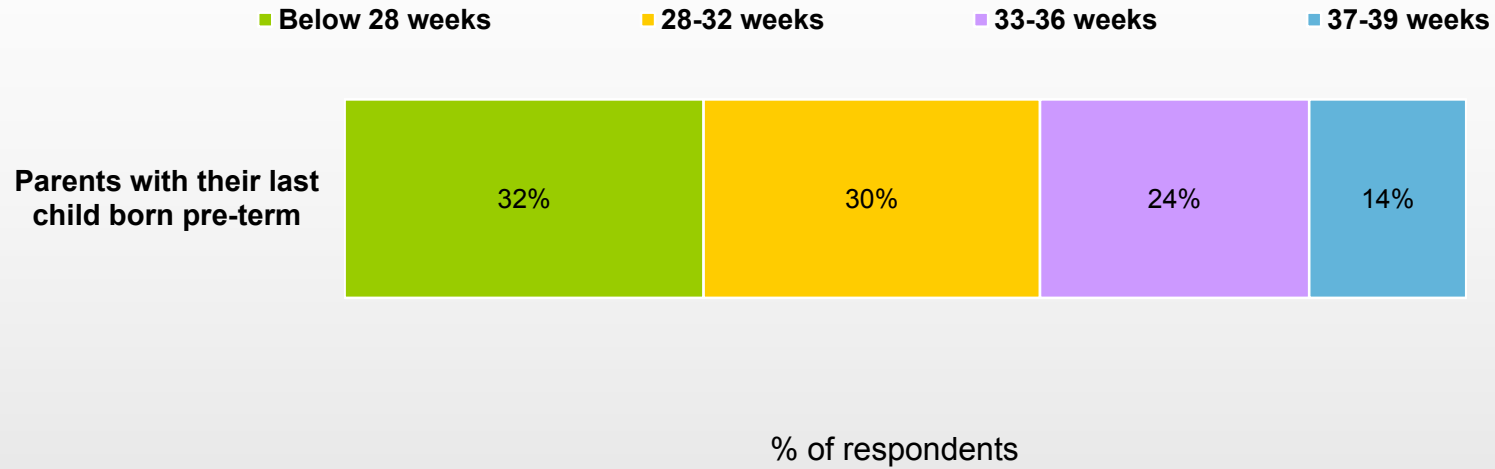
Base: 151 respondents
Q 3 When was your last baby born?

Last baby born was pre-term or full-term



Base: 138 respondents
Q 4 Please indicate if your last baby was born: pre term ,full term

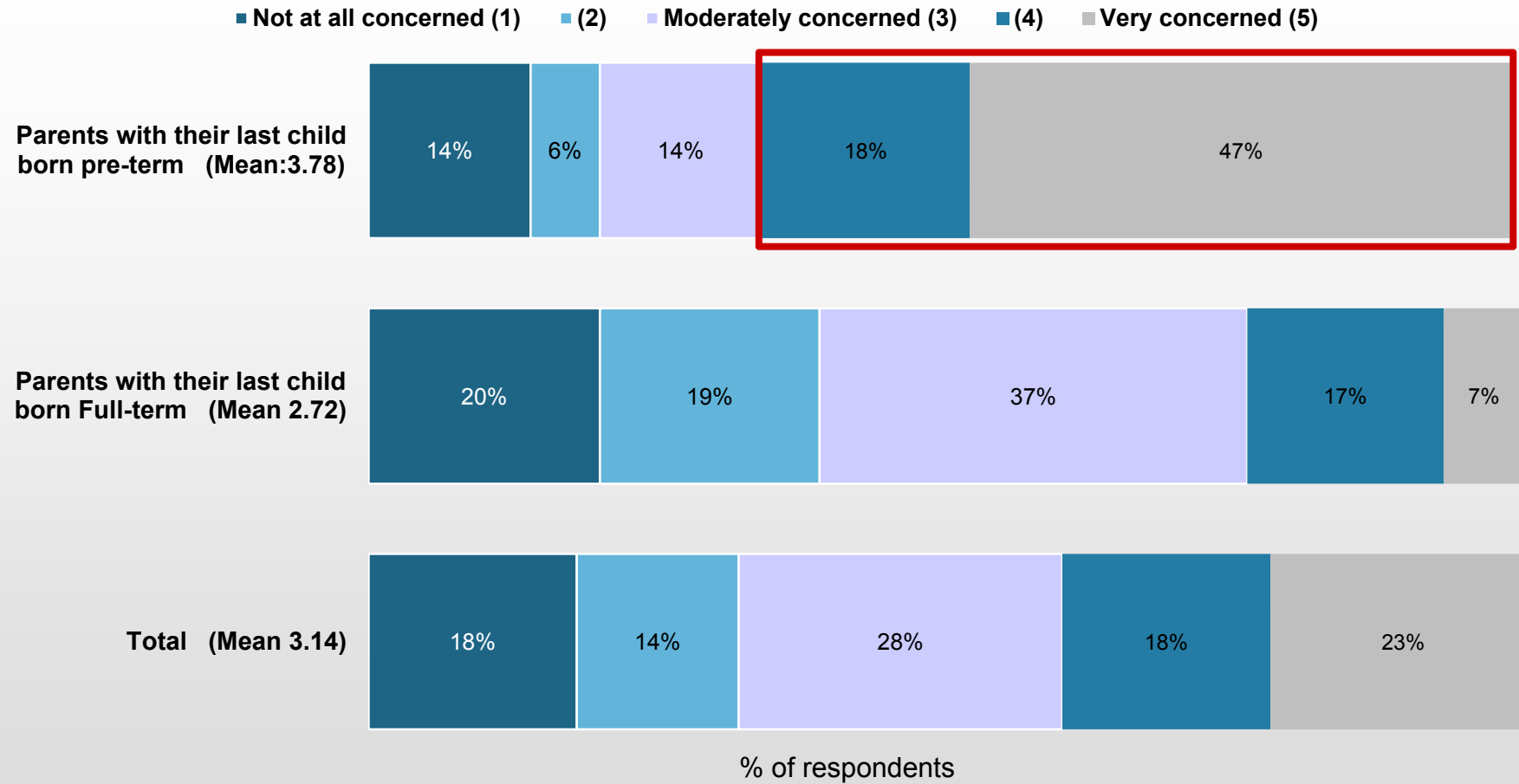
Gestational Age of Infant



Base: 50 respondents
Q 5 At what gestational age was your pre-term infant born?



Level of Concern About Premature Births



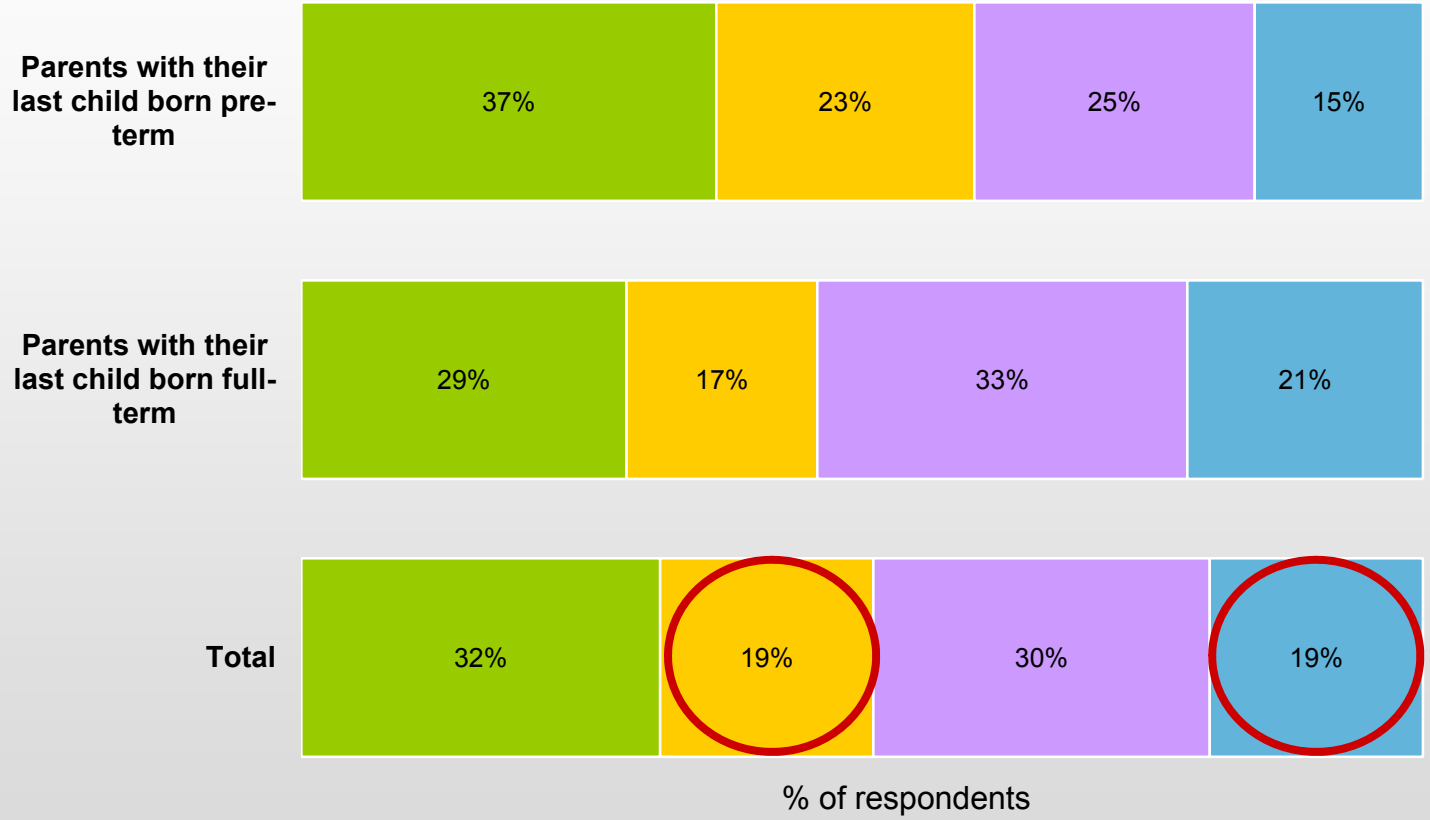
Those with their last child born pre-term are more concerned about the possibility of having a premature baby.

Base: 124 respondents

Q 6 During your pregnancy how concerned have you been/or were you about the possibility of having a premature baby? Please indicate your level of concern on a scale of 1 to 5:

Awareness of a premature birth

- When I/my partner became pregnant with my first child
- I was not aware of the possibility until I had my first child
- Before I/my partner became pregnant with my first child
- I was never aware of the possibility

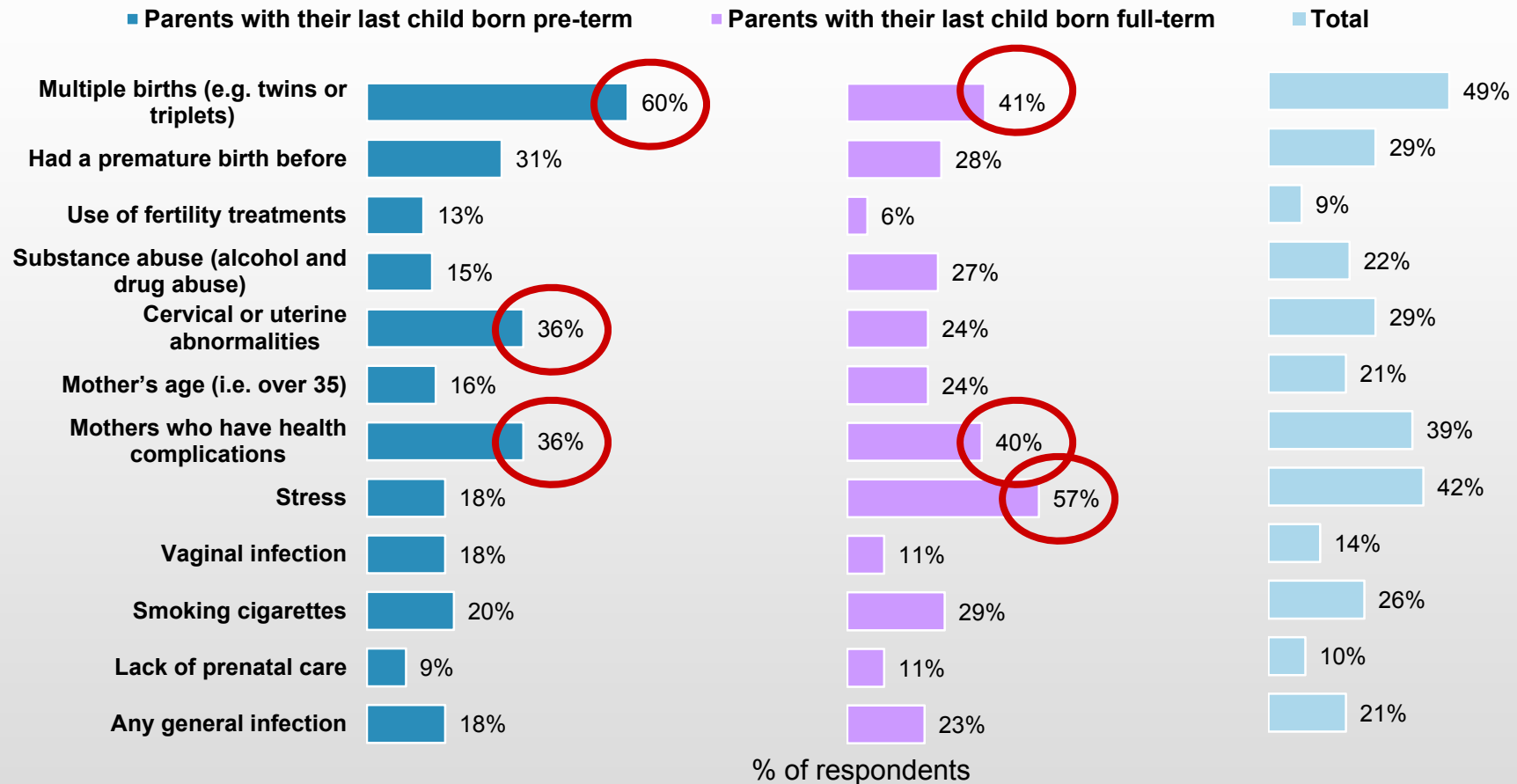


- Nearly 1 in 5 were never aware of the possibility of a premature birth and nearly 1 in 5 were not aware of the possibility until they had their first child.

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Section 2 Risks

Causes that could contribute to the birth of a premature baby



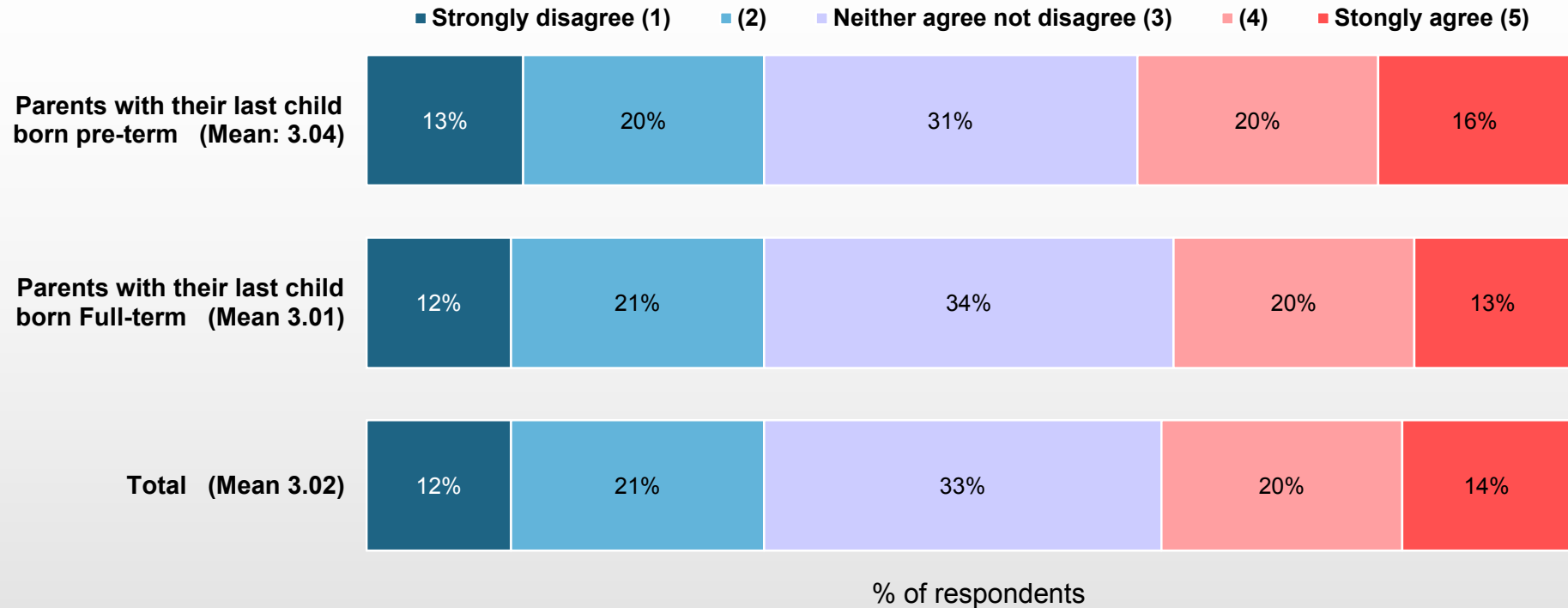
▪ The most common causes chosen by parents with the last child born pre-term were multiple births, mothers who have health complications, or cervical/uterine abnormalities. Parents with the last child born full-term chose stress most often, followed by multiple births and health complications in the mother.

Base: 137 respondents

Q.8 Following are various causes that could contribute to the birth of a premature baby. To the best of your knowledge, which of the following do you think represent the **3 most common factors**?



Parent was provided with appropriate information about premature births



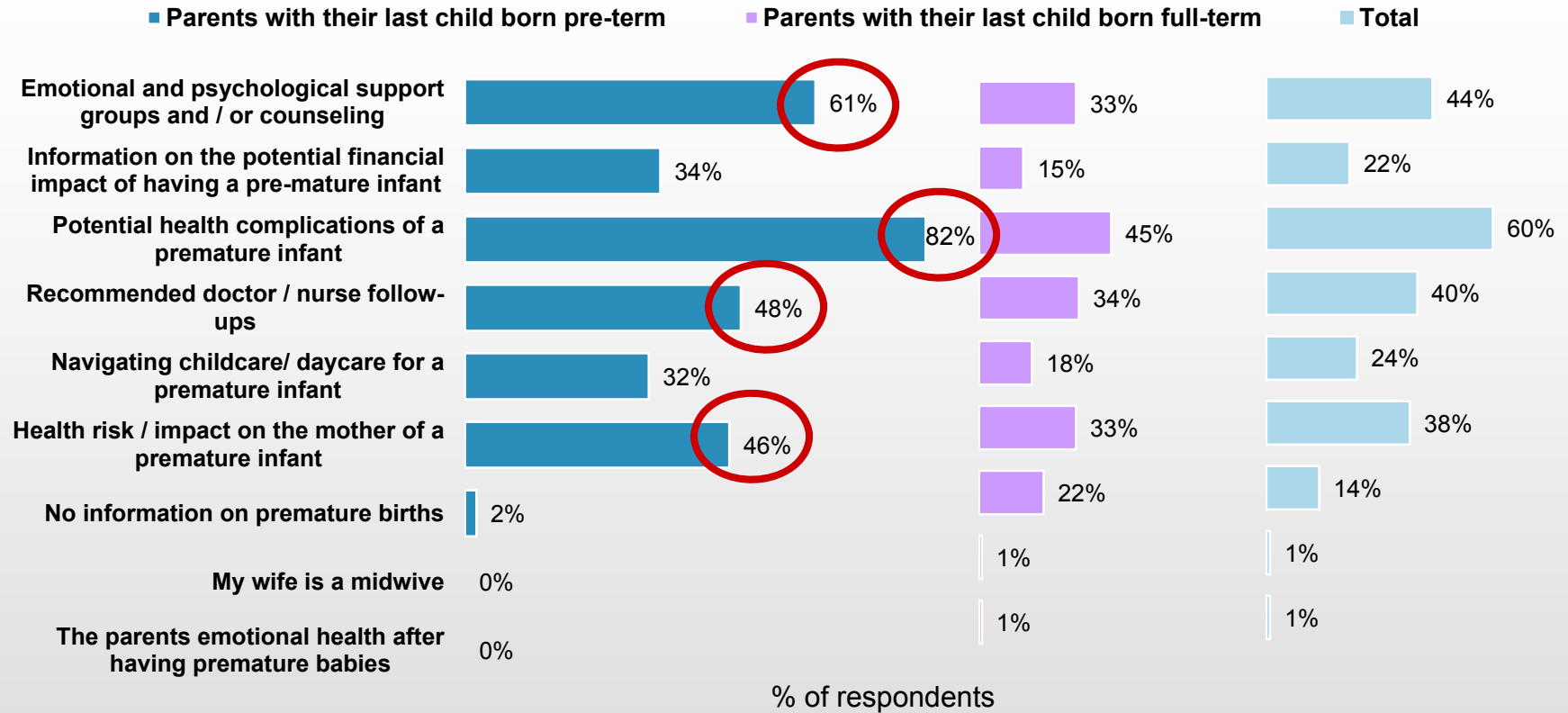
- Interestingly, the results from Irish Neonatal Health Alliance respondents were less positive, with a mean score of 2.77

Base: 121 respondents

Q 9 To what level do you agree with the following statement: My/my spouse's healthcare provider provided me/my spouse with the appropriate level of information about the risks associated with having a premature baby. Please indicate on a scale of 1 to 5.



Interest in knowing topics concerning premature birth



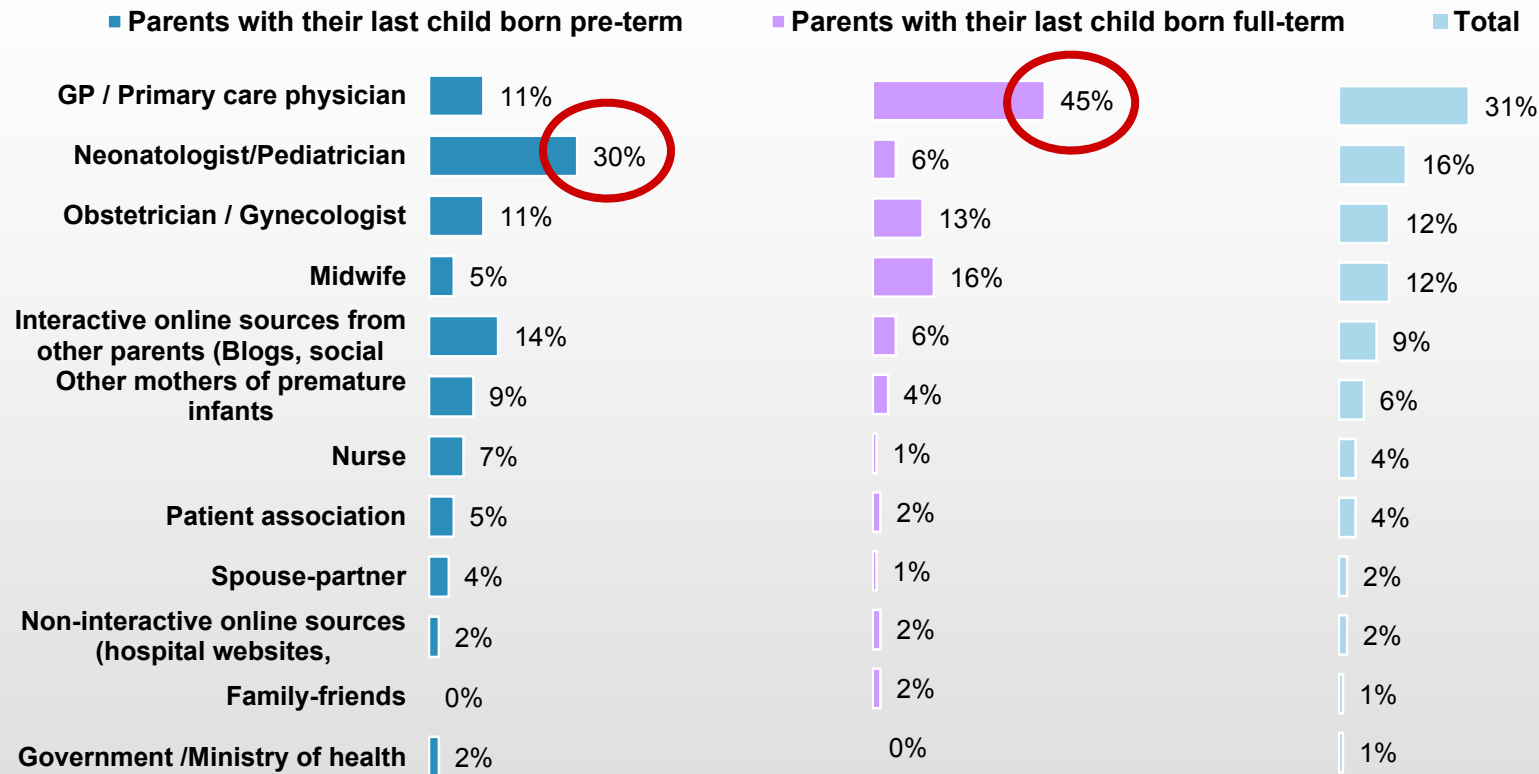
- Most parents whose last child was pre-term are interested in knowing about potential health complications of a premature infant, emotional and psychological support groups/counseling, recommended doctor/nurse follow-ups and health risk/impact on the mother of premature infant.
- Parents whose last child was full-term are interested in similar topics, but with fewer responses per topic.

Base: 138 respondents

Q.10 Which topics concerning premature birth are you interested in **knowing more about**?



Most comfortable sources to obtain information about the risks associated with premature births



- The highest response from parents whose first child was pre-term was that they were most comfortable obtaining information about the risks of premature births from Neonatologist/Paediatrician, while the highest response from parents whose first child was from their GP/Primary care physician.
- The highest response from parents via INHA was that they are most comfortable getting their information from Neonatologist/Paediatrician.

Base: 138 respondents

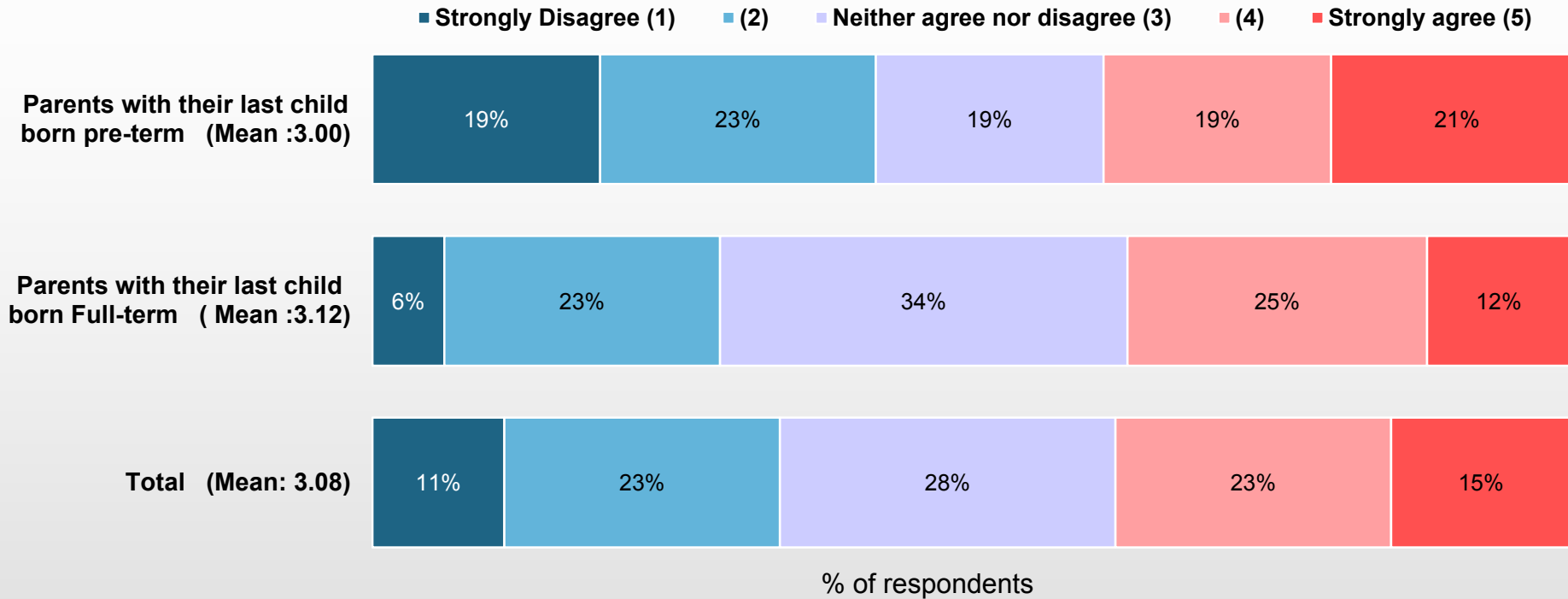
Q.11 Of the following information sources, which are you most comfortable utilizing to obtain information about the risks associated with premature births? (CHOOSE ONE)

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Section 3 Complications



Before pregnancy, were parents aware of health complications associated with prematurity?



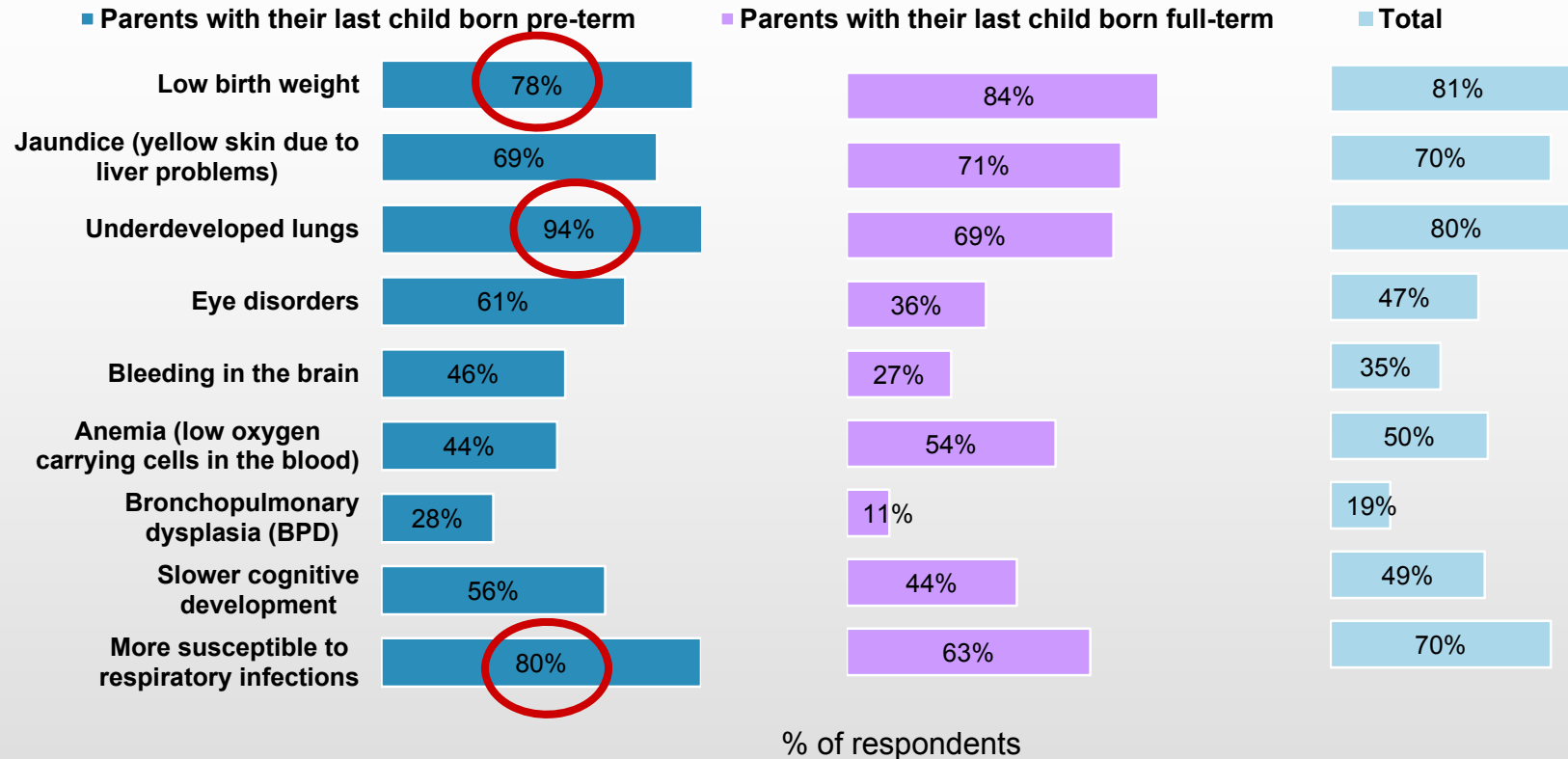
- Parents whose last child was pre-term were evenly split on their views on this statement – approximately 40% either agreed or disagreed, with nearly 1 in 5 neither agreeing nor disagreeing. INHA respondents were also split on their view with more (53%) disagreeing than agreeing (37%).
- Parents whose last child was full-term were relatively evenly split between agreeing, being neutral and disagreeing.

Base: 120 respondents

Q 12 To what level do you agree with the following statements? Before expecting a baby or early on in pregnancy, I/my spouse was aware of the health complications associated with having a premature baby. Please indicate on a scale of 1 to 5.



Potential complications of the premature birth of an infant



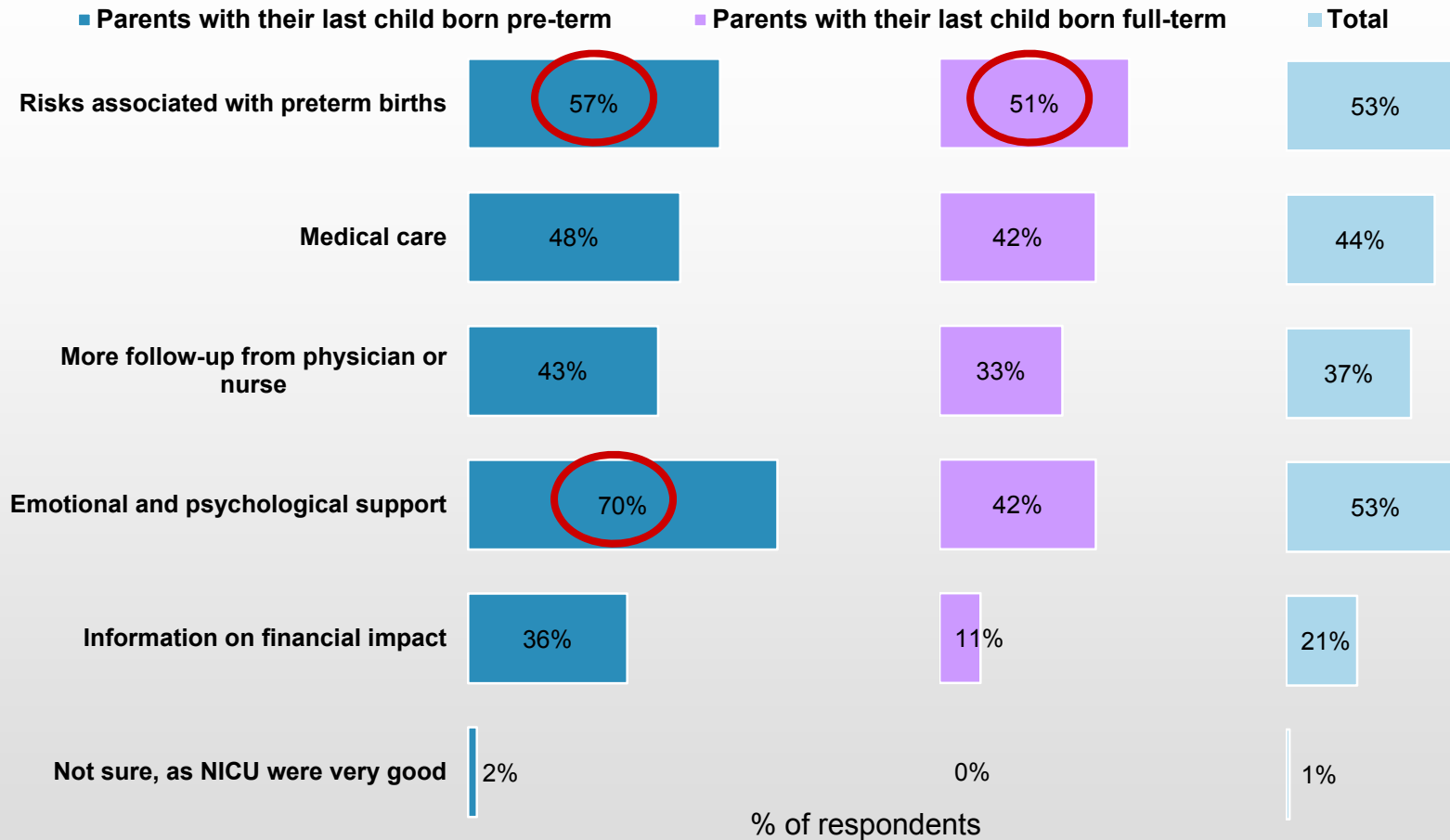
- The top things parents whose last child was pre-term heard/received information about potential complications were: Underdeveloped lungs, more susceptibility to respiratory infections, low birth weight. For parents whose last child was full-term it was low birth weights, jaundice and underdeveloped lungs.
- INHA respondents cited underdeveloped lungs, susceptibility to respiratory infections, low birth weight and eye disorders.

Base: 124 respondents

Q.13 Have you heard or received information about any of the following as potential complications of the premature birth of an infant? (ANSWER YES/NO/I AM NOT FAMILIAR WITH THIS TERM)



Additional information that parents would like to receive in the NICU

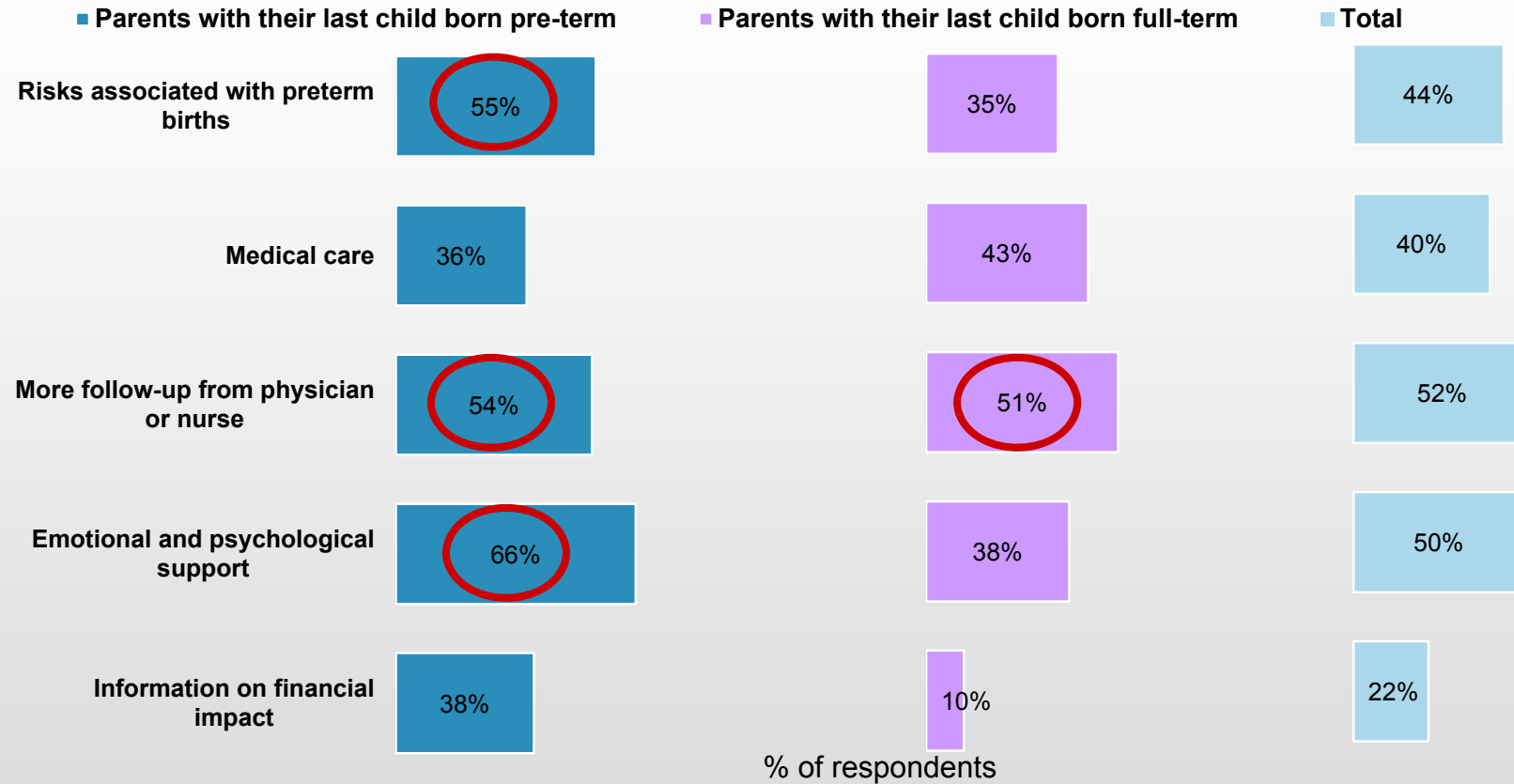


- 7 out of 10 parents whose last child was pre-term would like to have received more information about emotional and psychological support, while 57% of them would have liked more information about risks associated with pre-term births.
- 83% of INHA respondents would like to have received more information on emotional and psychological support
- Over half of parents whose last child was full-term would have like to have received more information about risks associated with preterm birth.

Base: 135 respondents

Q.14 What additional information or support would you have liked to have received when your baby was admitted to the NICU? (Please select all that apply)

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- Again nearly 7 out of 10 parents whose last child was pre-term would like to have received more information about emotional and psychological support , while 55% of them would have liked more information about the risks associated with pre-term births and 54% would like to receive more information on follow-up from physician or nurse.
- Just over half of parents whose last child was full-term would have liked more information on follow-up from physician or nurse

Base: 133 respondents

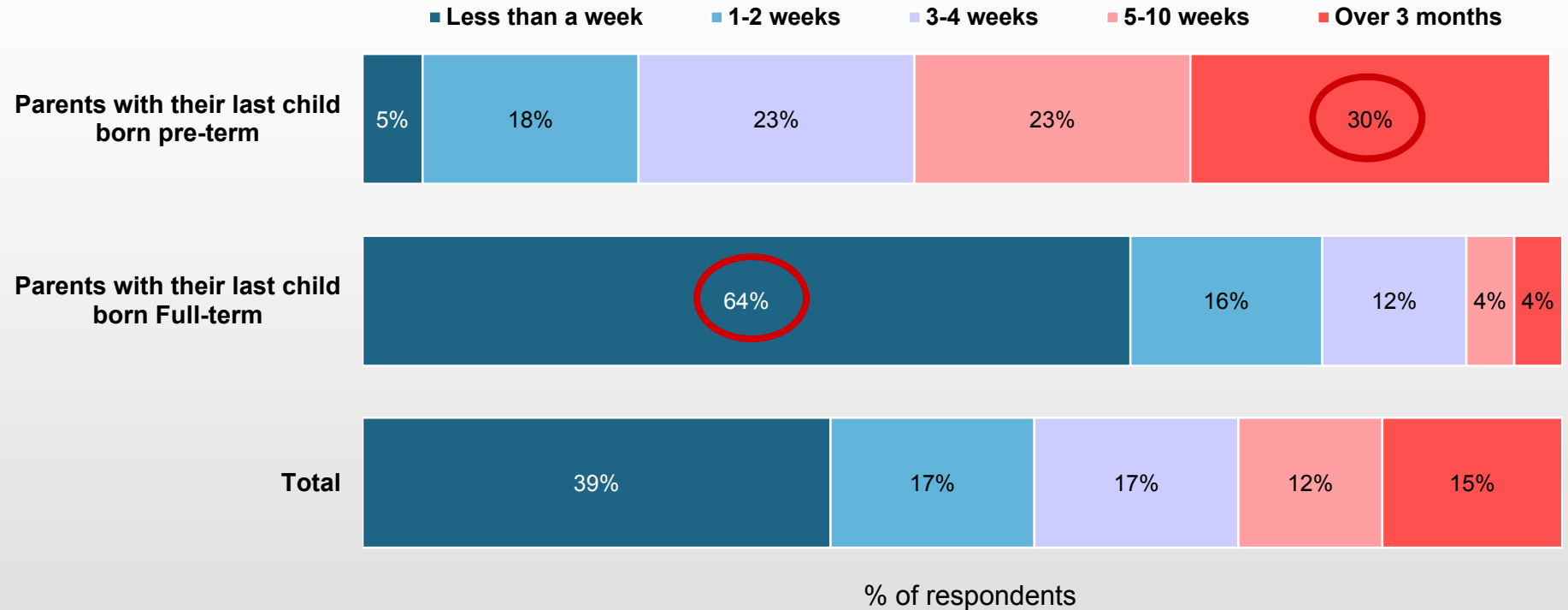
Q.14 a What additional information or support would you have liked to receive upon the discharge of your baby from hospital? (Please select all that apply)

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Section 4
Experiences of premature birth



Time spent by infant in the hospital immediately after birth



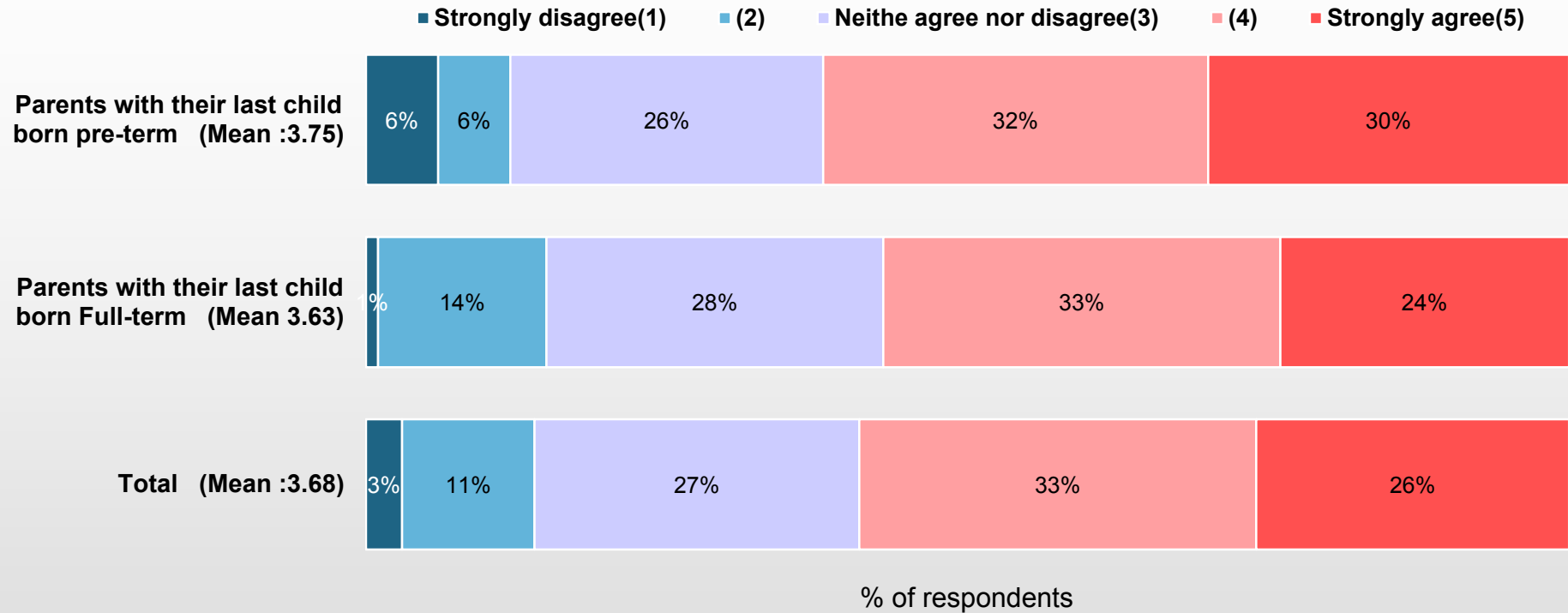
- 3 out of 10 pre-term babies spend over 3 months in hospital immediately after birth.
- For full-terms, nearly 2/3 stay in hospital for less than a week.

Base: 132 respondents

Q 15 How long did your premature infant spend in the hospital immediately after birth before being able to come home? (CHOOSE ONE)



Agreement that the mother of the baby has a good relationship with her main doctor



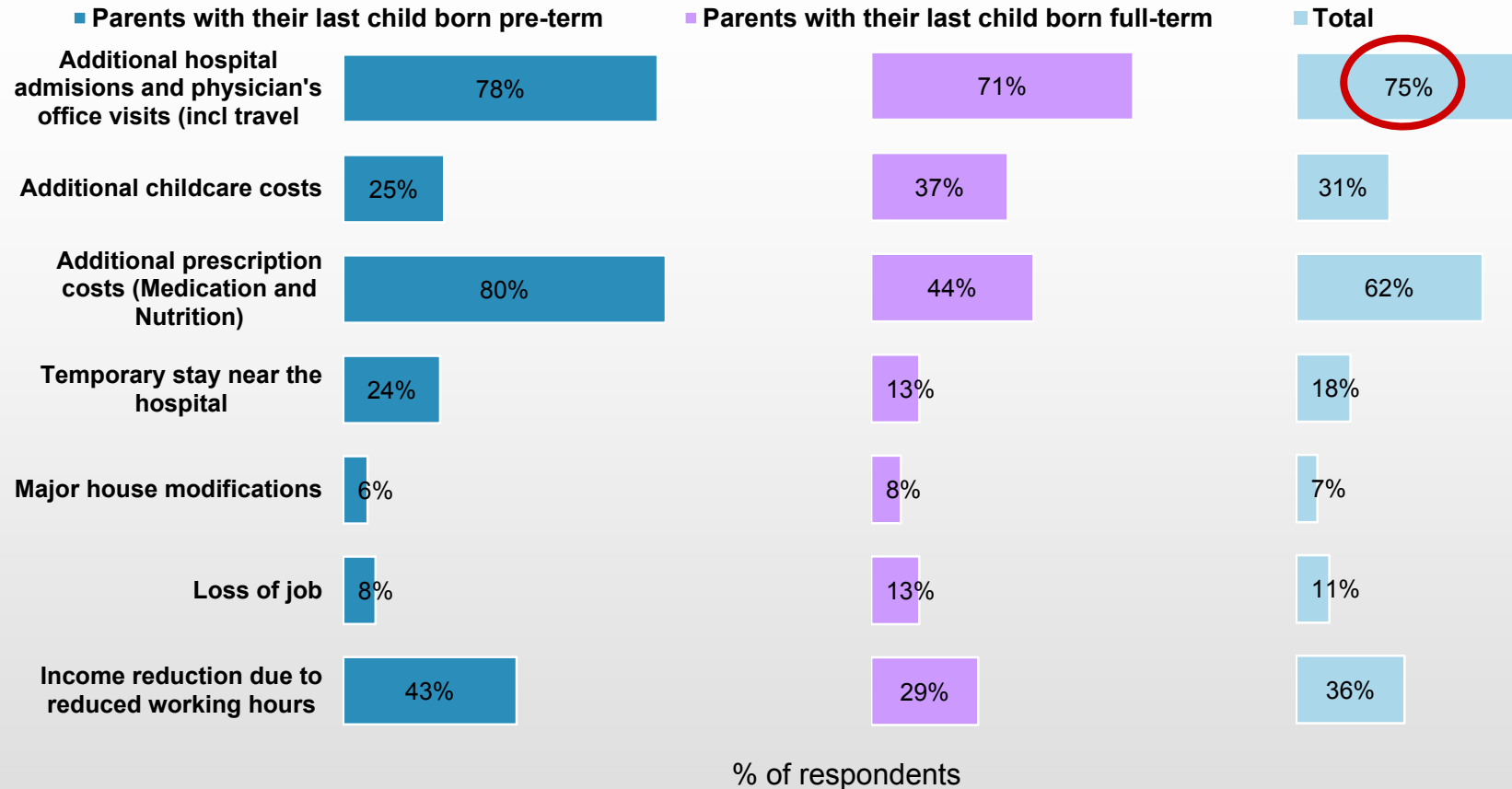
- About 60% of parents agreed that they have a good relationship with their main doctor/healthcare professional.

Base: 129 respondents

Q 16 To what level do you agree with the following statement: //the mother of my baby has/have a very good relationship with my main doctor/healthcare professional? Please indicate on a scale of 1 to 5:



Financial impact of having a premature baby

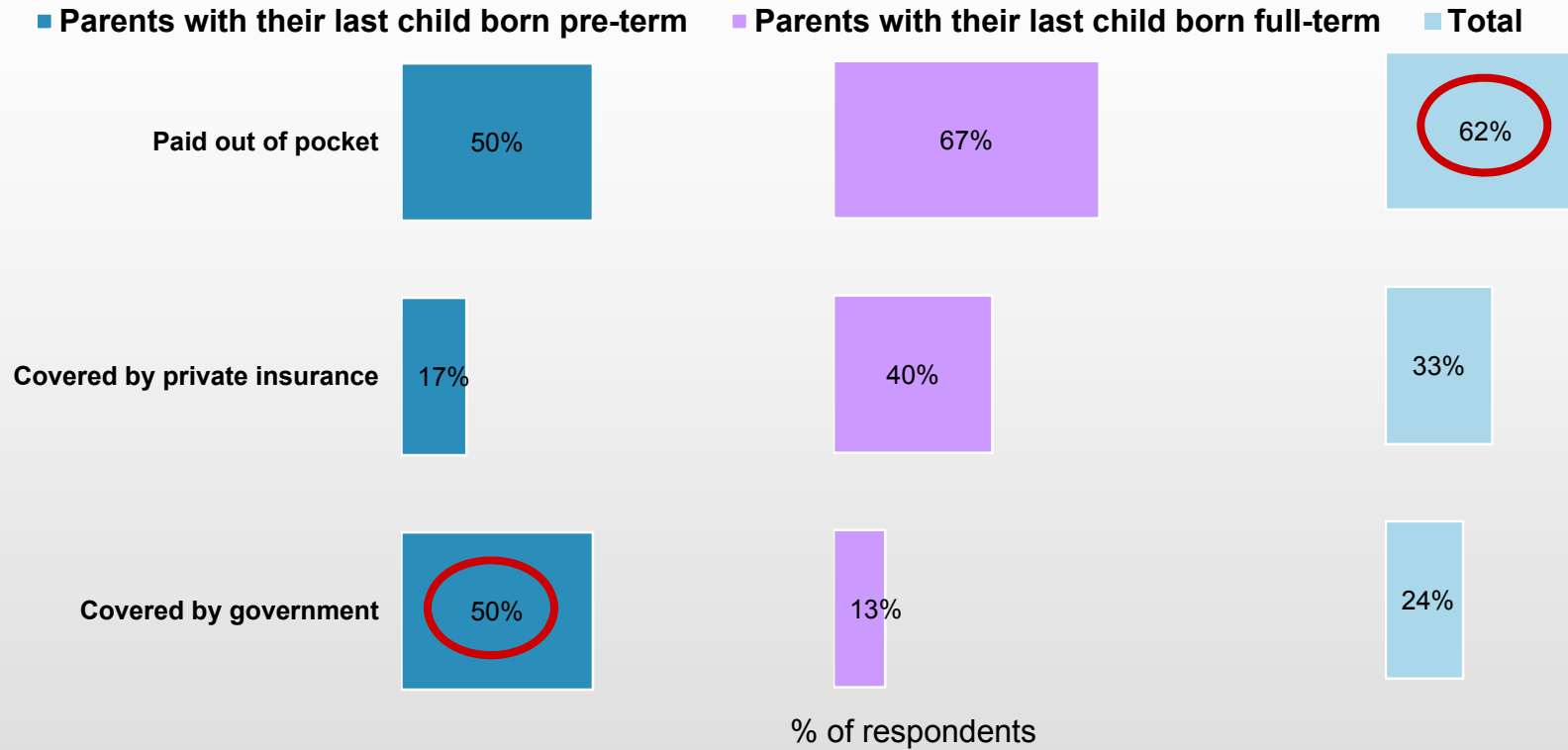


- Overall, additional hospital admissions and physicians office visits, have the biggest effect followed by additional prescription costs.

Base: 103 respondents

Q.17 Which of the following describes the financial impact or costs that having a premature baby had on you and/or your immediate family?

Payment of additional medical costs



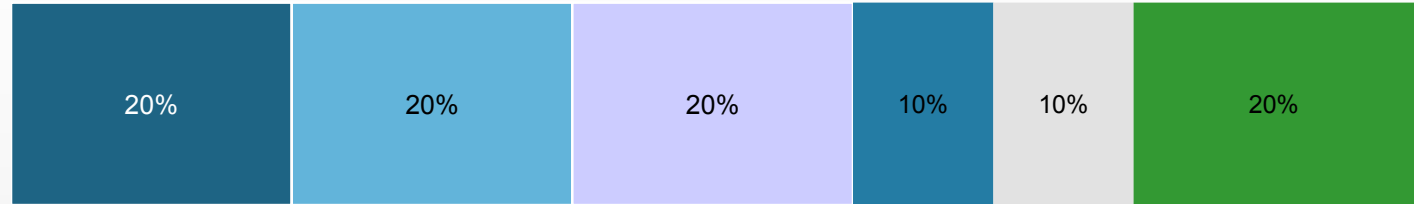
Overall additional medical costs are mainly paid out of pocket with some covered by government. For pre-terms there seems to be more costs covered by government.

Base: 21 respondents * (Very small)
 Q 18 How were the additional medical costs (prescriptions, hospitalization, physician cost) paid for?

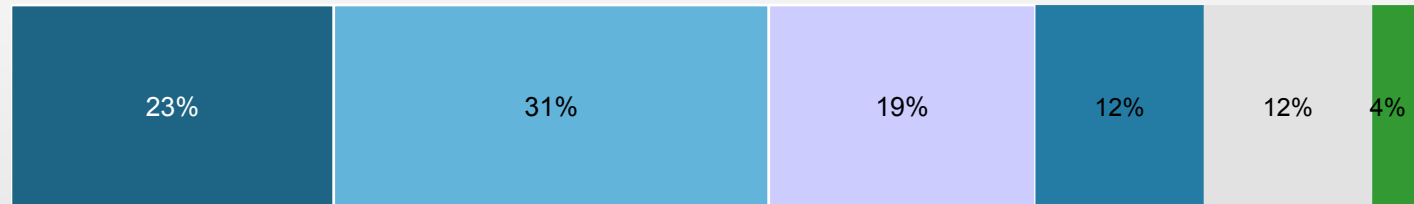
Working days missed beyond leave to provide care to infant

■ 0 days ■ 1-3 days ■ 4-6 days ■ 1-2 weeks ■ 2-3 weeks ■ more than 3 weeks

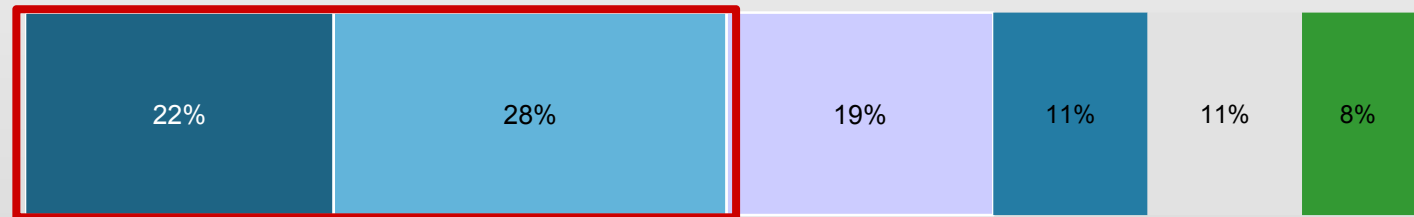
Parents with their last child born pre-term



Parents with their last child born Full-term



Total



% of respondents

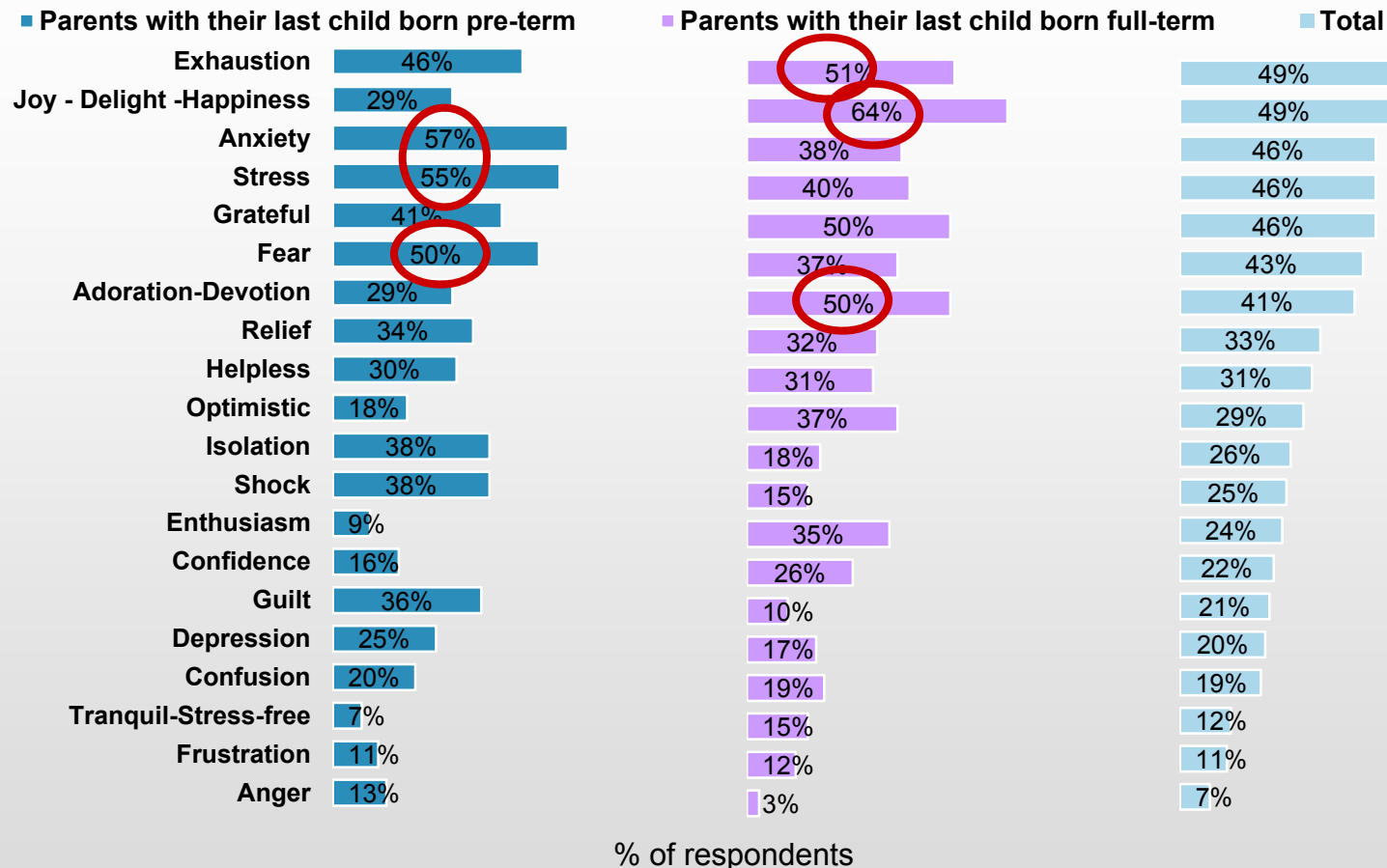
▪ Nearly 5 out of 10 respondents answering this question advised that they missed up to 6 days.

Base: 36 respondents (very small)

Q 19 Since the birth of your baby, please indicate how many days of work you and/or your spouse missed to provide care to your infant beyond the maternity /paternity leave allowed by your government /employer?



Feelings concerning the experience of caring for last baby as an infant



- For parents whose last child was full-term, 'Joy-Delight-Happiness', 'Exhaustion', 'Grateful', 'Adoration-Devotion' are the phrases that were most commonly used to describe parents' feelings.
- For parents whose last child was pre-term 'Anxiety', 'Stress', 'Fear' are the words used most.

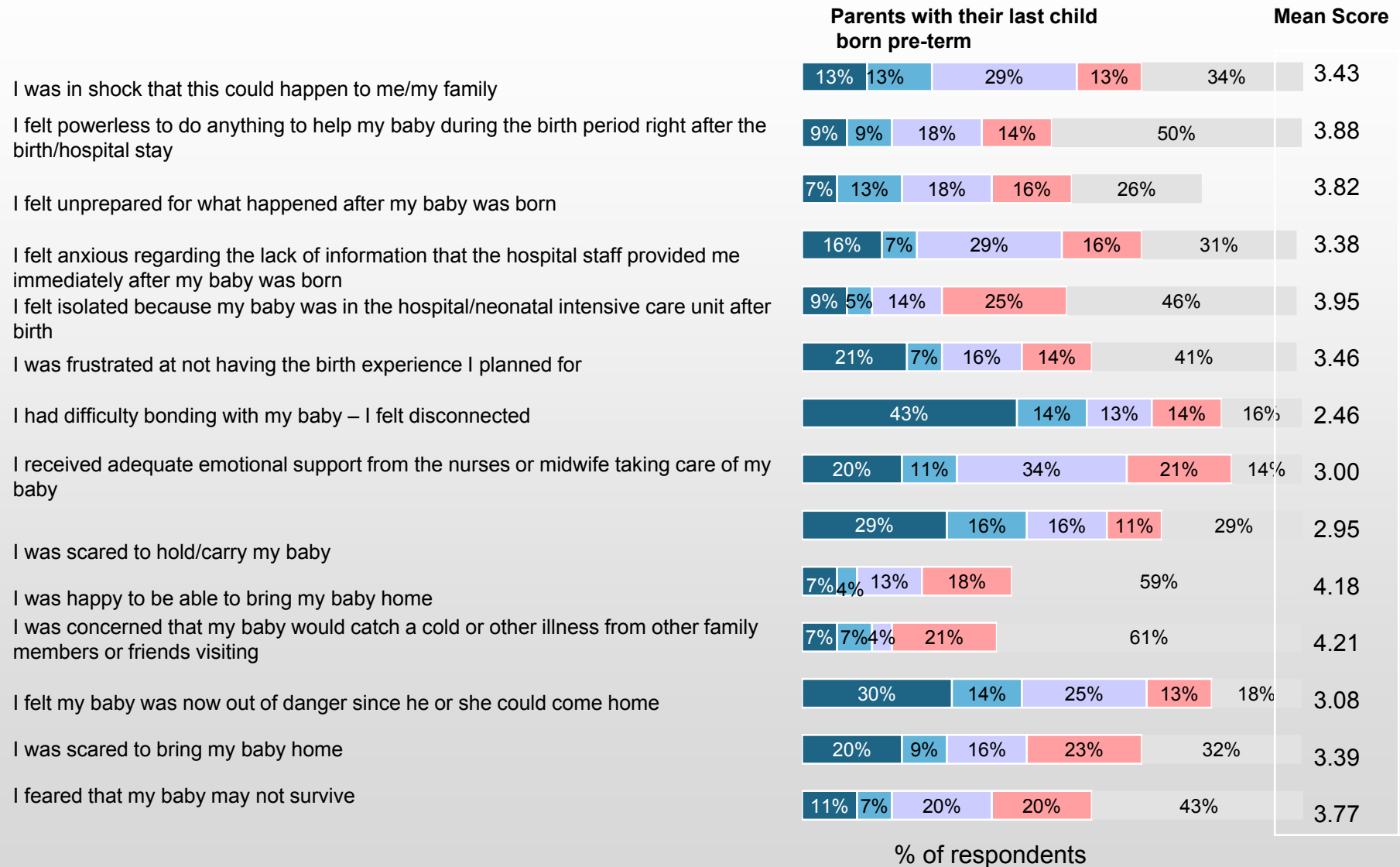
Base: 134 respondents

Q.20 Which of the words listed below best describe your feelings concerning the experience of caring for your last baby as an infant? Please select the 6 words that best describe the dominant feelings you experienced.



Level of Agreement with Experiences Following Birth of Infant – pre-term

■ Strongly disagree
 ■ 2
 ■ Neither agree not disagree
 ■ 4
 ■ Strongly agree

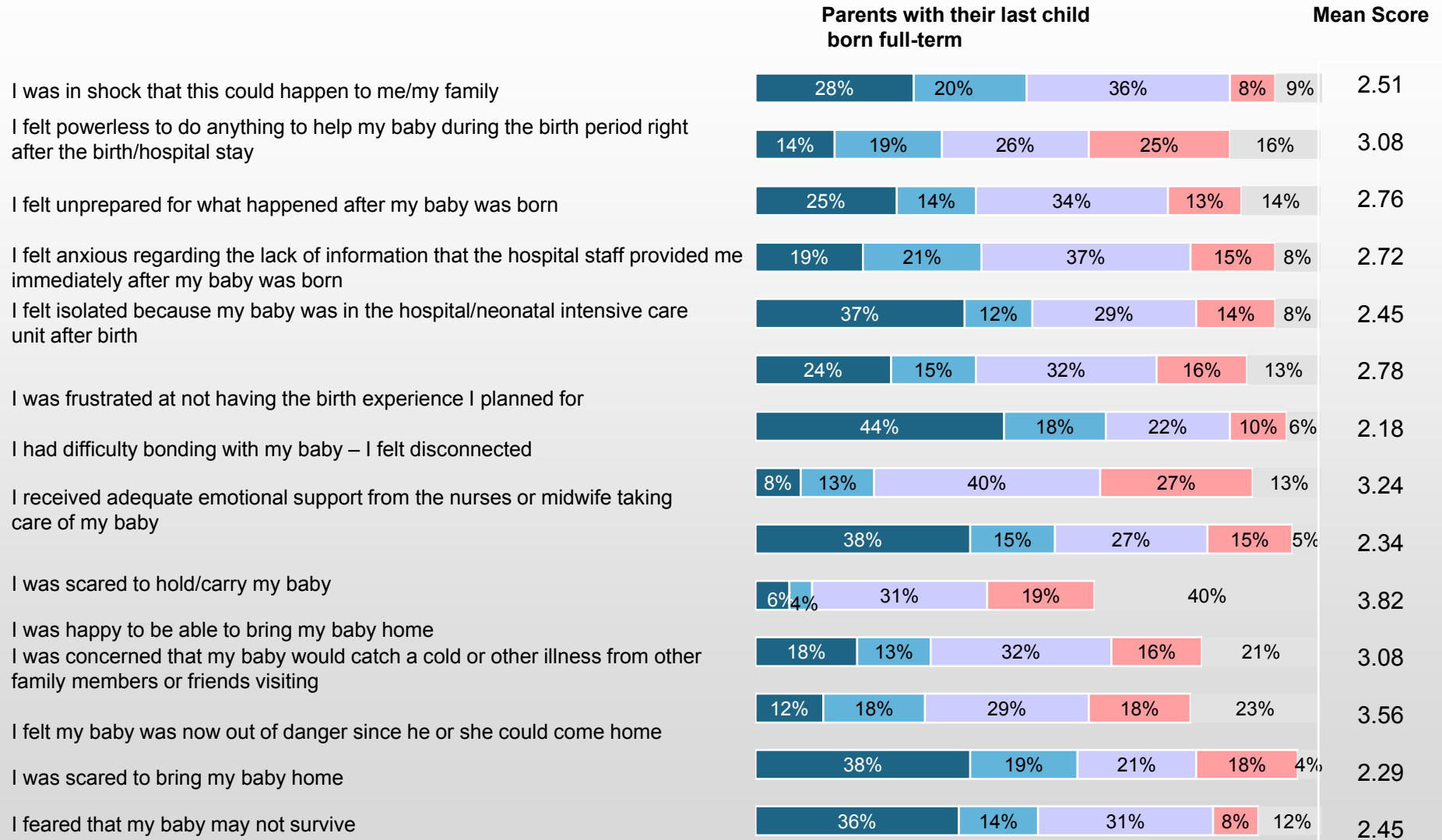


Q.21 Please think about your experiences following the birth of your last baby and indicate your level of agreement with each of the statements below.



Level of Agreement with Experiences Following Birth of Infant – full-term

■ Strongly disagree
 ■ 2
 ■ Neither agree not disagree
 ■ 4
 ■ Strongly agree



% of respondents

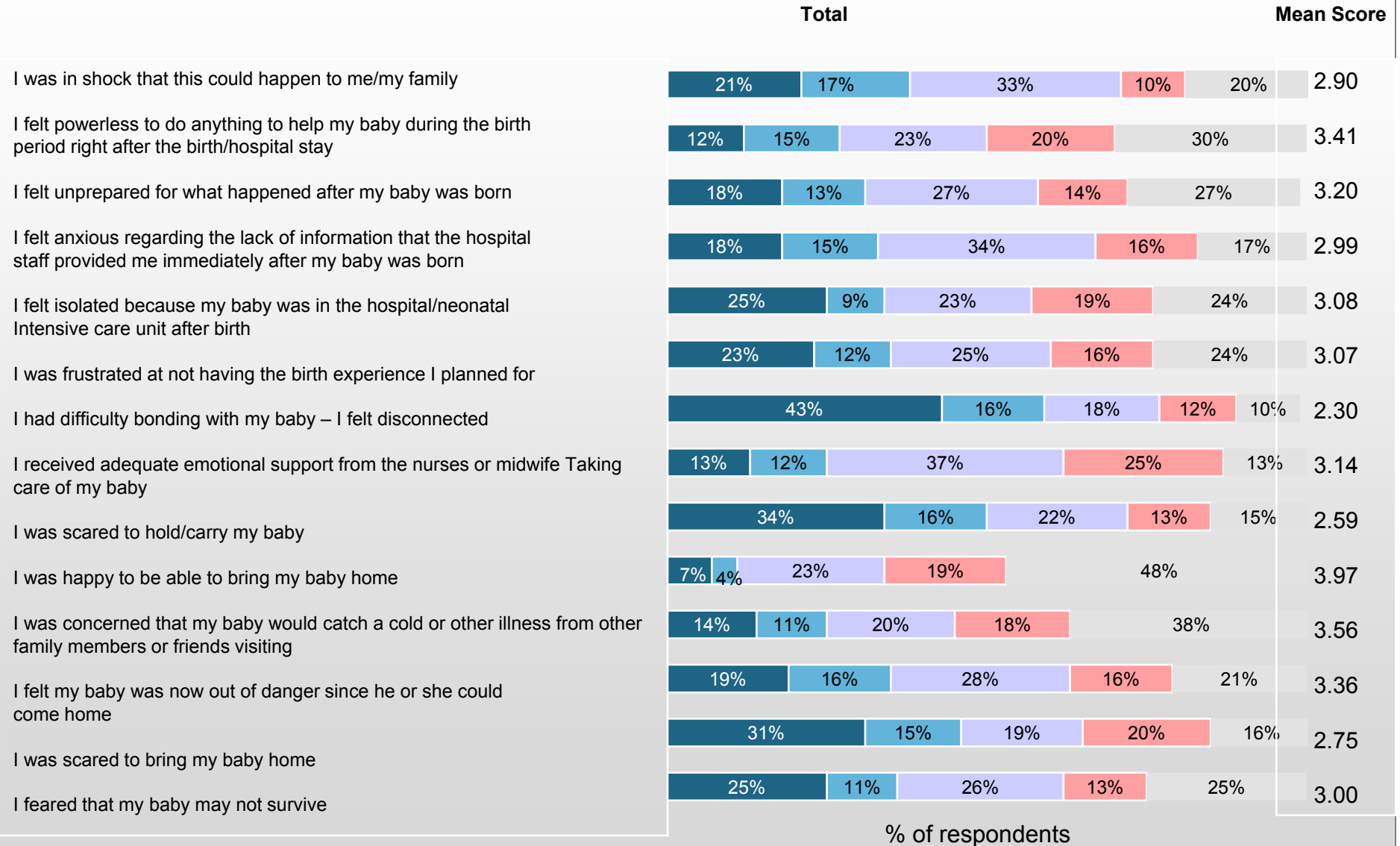
% of respondents

Q.21 Please think about your experiences following the birth of your last baby and indicate your level of agreement with each of the statements below.



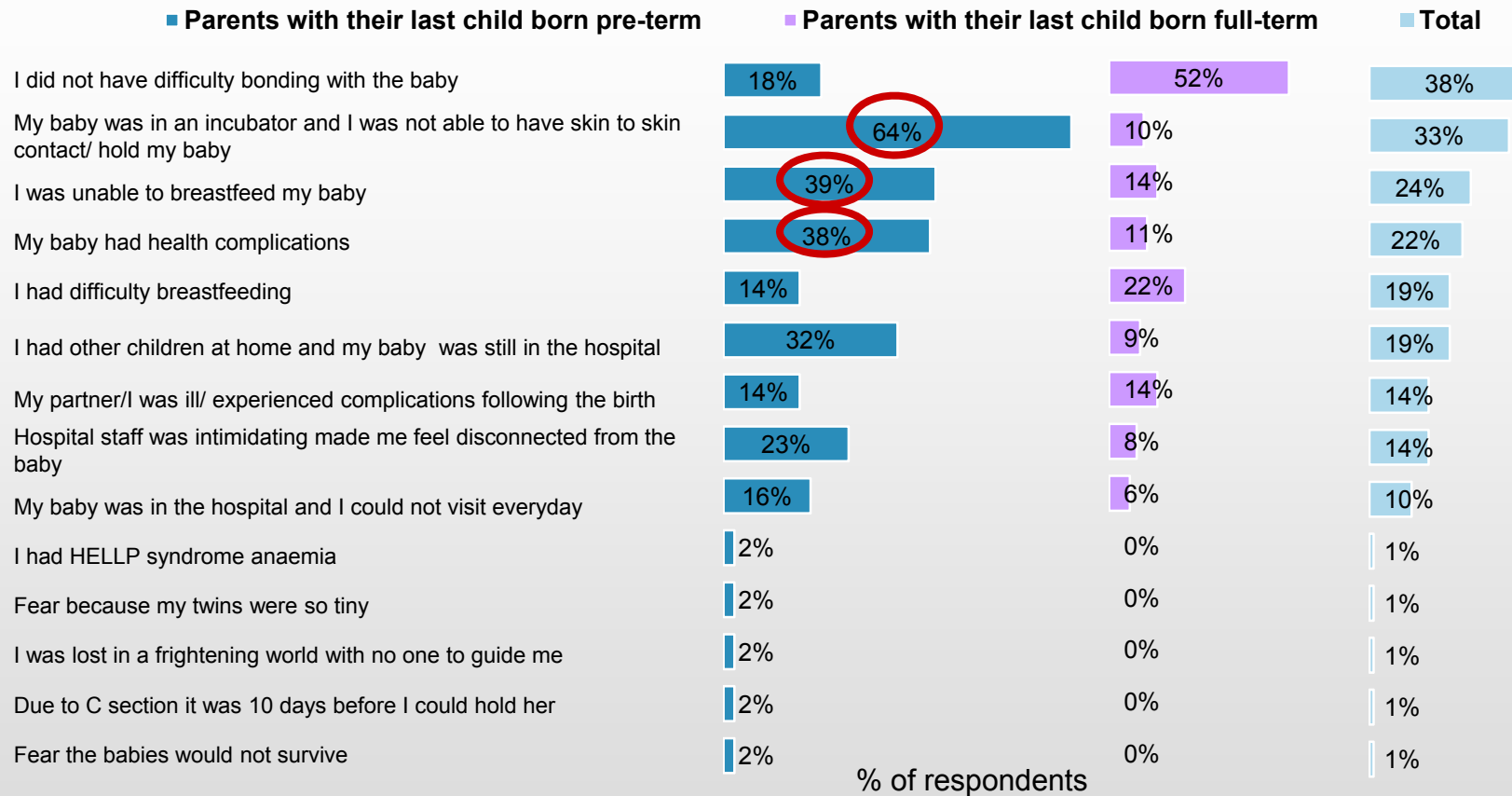
Level of Agreement with Experiences Following Birth of Infant - Total

■ Strongly disagree
 ■ 2
 ■ Neither agree not disagree
 ■ 4
 ■ Strongly agree



Q.21 Please think about your experiences following the birth of your last baby and indicate your level of agreement with each of the statements below.

abbvie Factors that made difficult to bond with baby



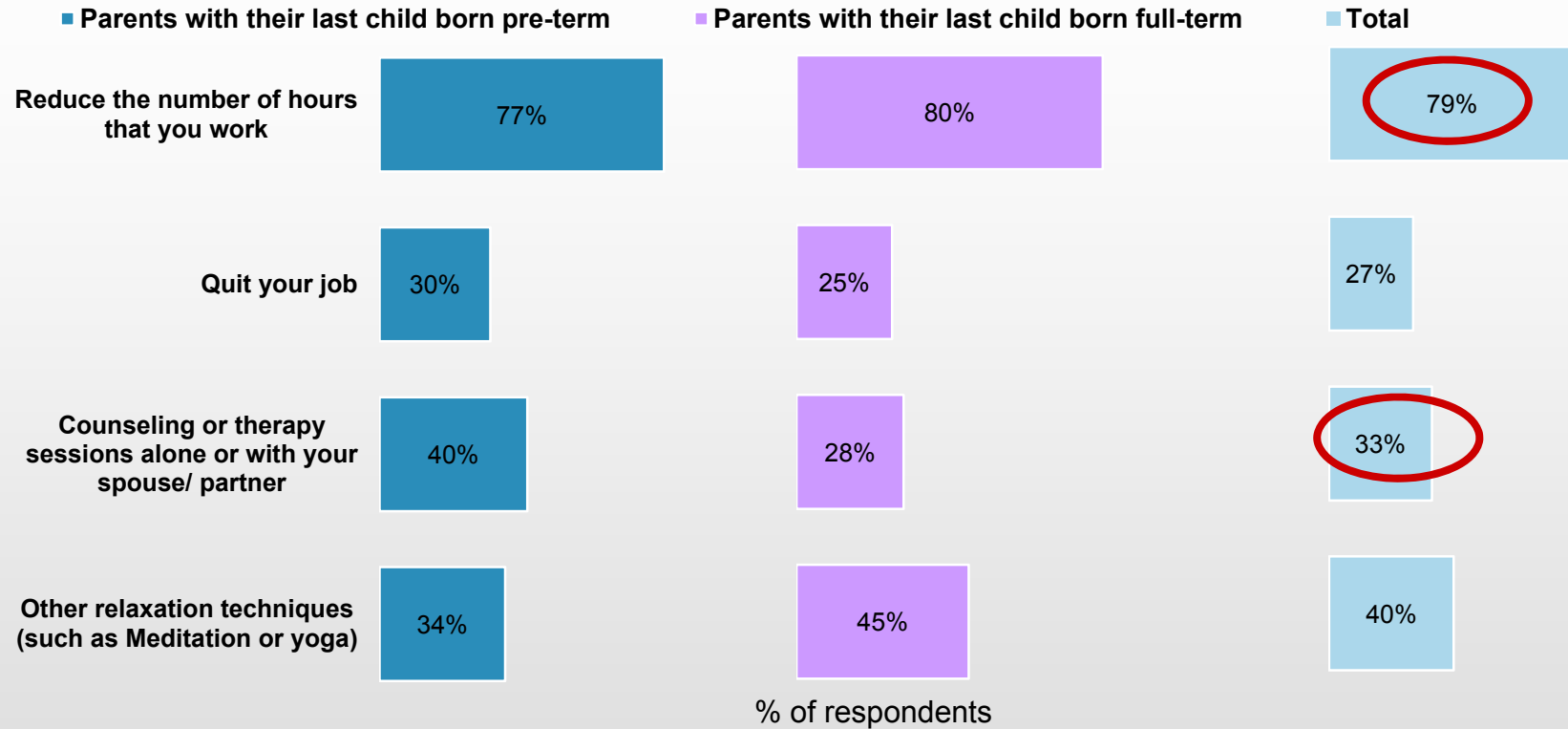
- The most common reasons why parents found it difficult to bond with their baby were their baby being in an incubator, being unable to breastfeed, and health complications of their baby made it difficult to bond with their baby.

Base: 135 respondents

Q.22 Please think about how you **first bonded with your baby**. Which of the following factors made it difficult for you bond with your baby?



Activities to help cope with the physical and emotional stress of being a new mother/father

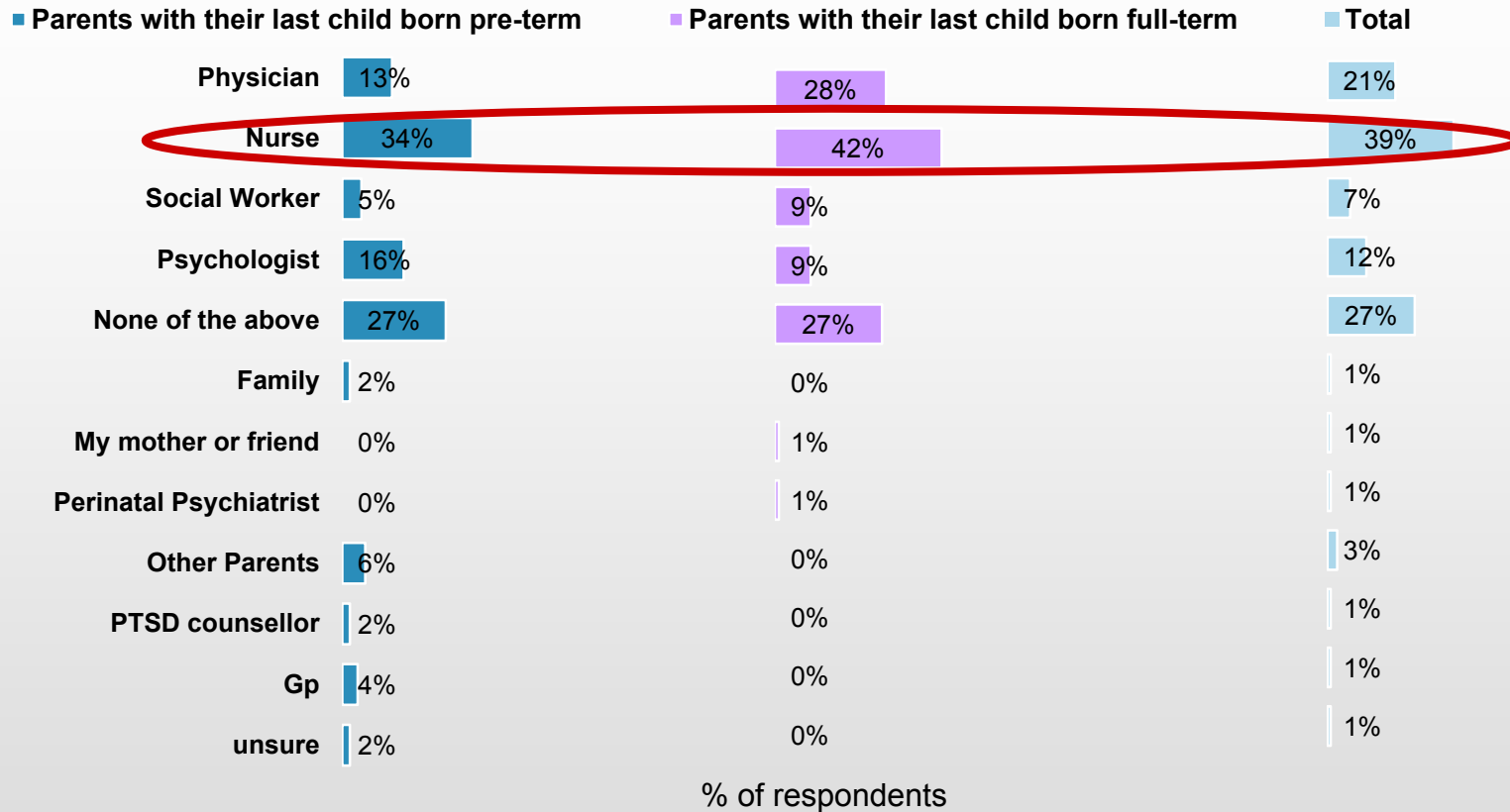


- Overall, nearly 8 out of 10 have already or will in the future reduce the number of hours that they work, with nearly 1 in 3 of those answering that they have or will in the future quit their jobs.

Base: 112 respondents

Q. 23 What activities and/or changes have you made/will you make to help cope with the physical and emotional stress of being a new mother/father

Counselor to help cope with the physical and emotional stress of being a new mother/new father



- The most common first choice for a counsellor to help cope with the physical and emotional stress was a nurse.

Base: 135 respondents

Q. 24 Who was/would be your first choice for a counselor to help cope with the physical and emotional stress of being a new mother/new father?

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Section 5 Respiratory Infection

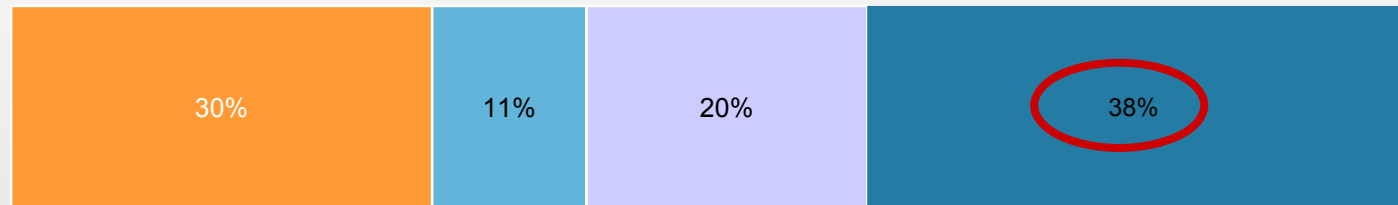
Season when the risk is at its highest for an infant to contract respiratory infections

■ Winter to spring
 ■ Spring to summer
 ■ Autumn/fall to end of spring
 ■ I don't know

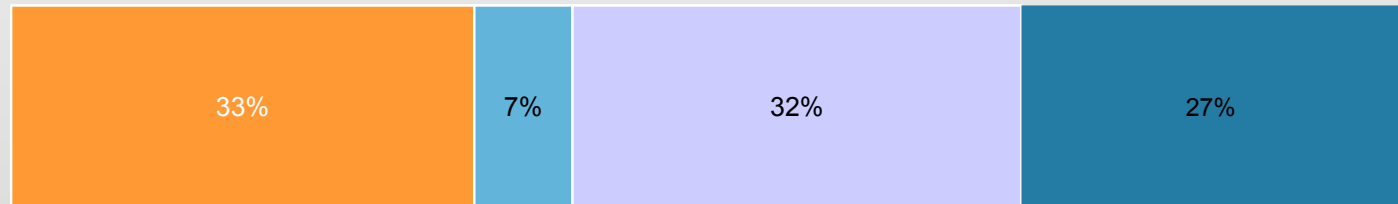
Parents with their last child born pre-term



Parents with their last child born Full-term



Total



- Nearly half of parents whose last child was pre-term think the highest risk is during the period Autumn to end of Spring (48%), and then 38% in Winter to Spring period.
- Parents whose last child was full-term were less sure, with nearly 4 out of 10 answering that they don't know.

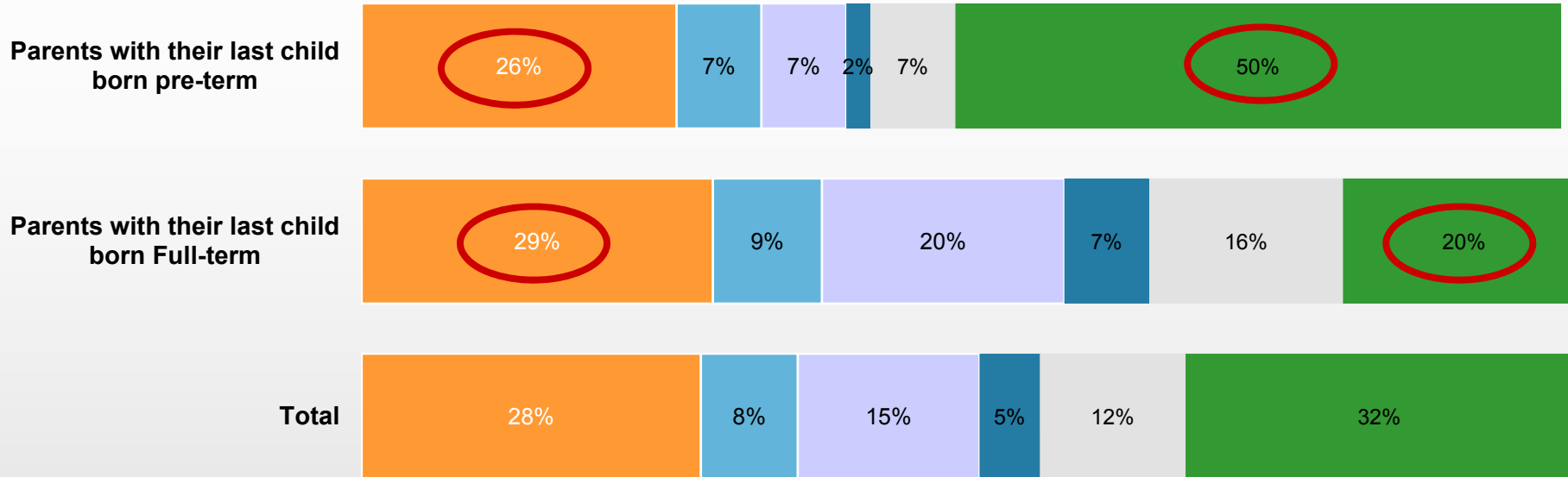
Base: 135 respondents

Q 25 Do you know when the risk is at its highest for an infant to contract respiratory infections?



Parents' views on what the top risk factor is for respiratory infection

% of respondents

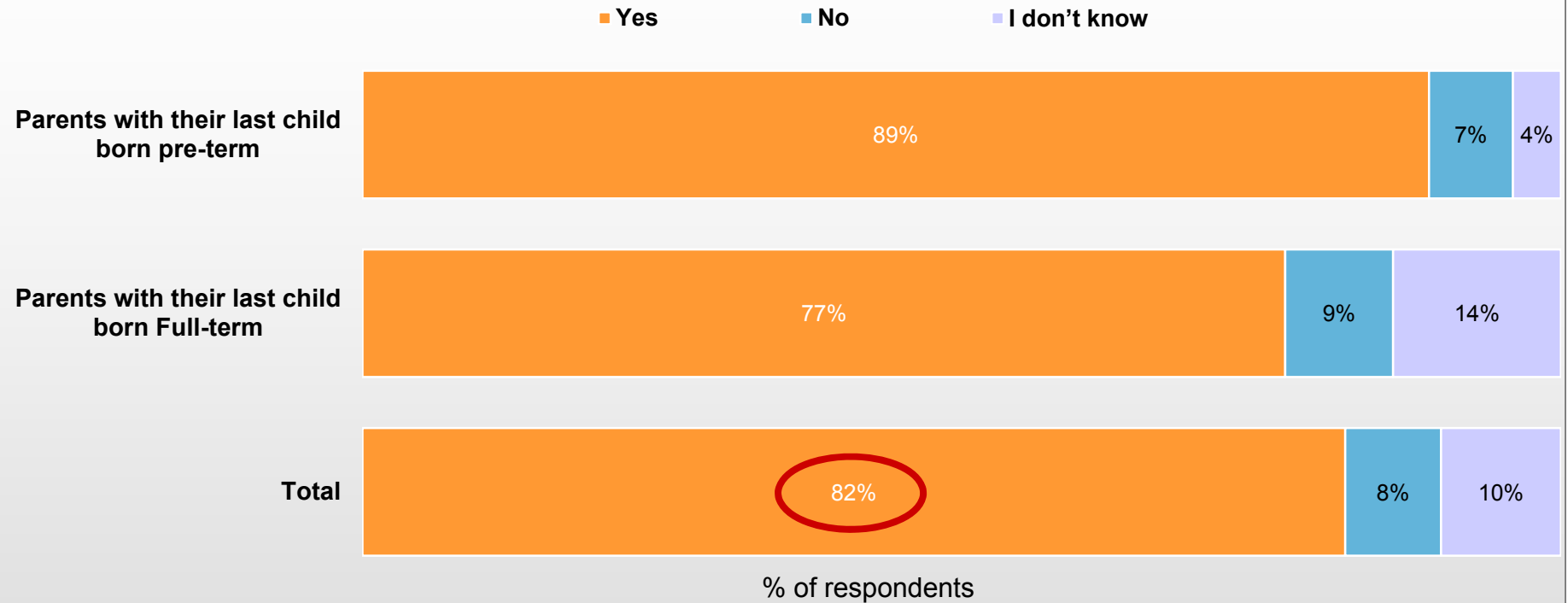


- Age of the baby at the start of respiratory syncytial virus (RSV) season
- Breast-feeding for less than 2 months total
- School age siblings
- More than four residents and visitors at home
- Family history of wheezing
- Gestational age of the baby at birth

- Half of parents whose last baby was pre-term think the biggest risk factor is gestational age of the baby at birth while over a quarter of them think the age of the baby at the start of the respiratory syncytial virus (RSV) season.
- For parents whose last child was full-term, 1 in 5 think it is the gestational age while nearly 3 out of 10 think it's the age of the baby at the start if the RSV season.

Base: 130 respondents
Q 26 Which of the following do you think are risk factors for respiratory infection?

abbvie Are parents aware of the increased susceptibility of pre-term infants to respiratory infections?"

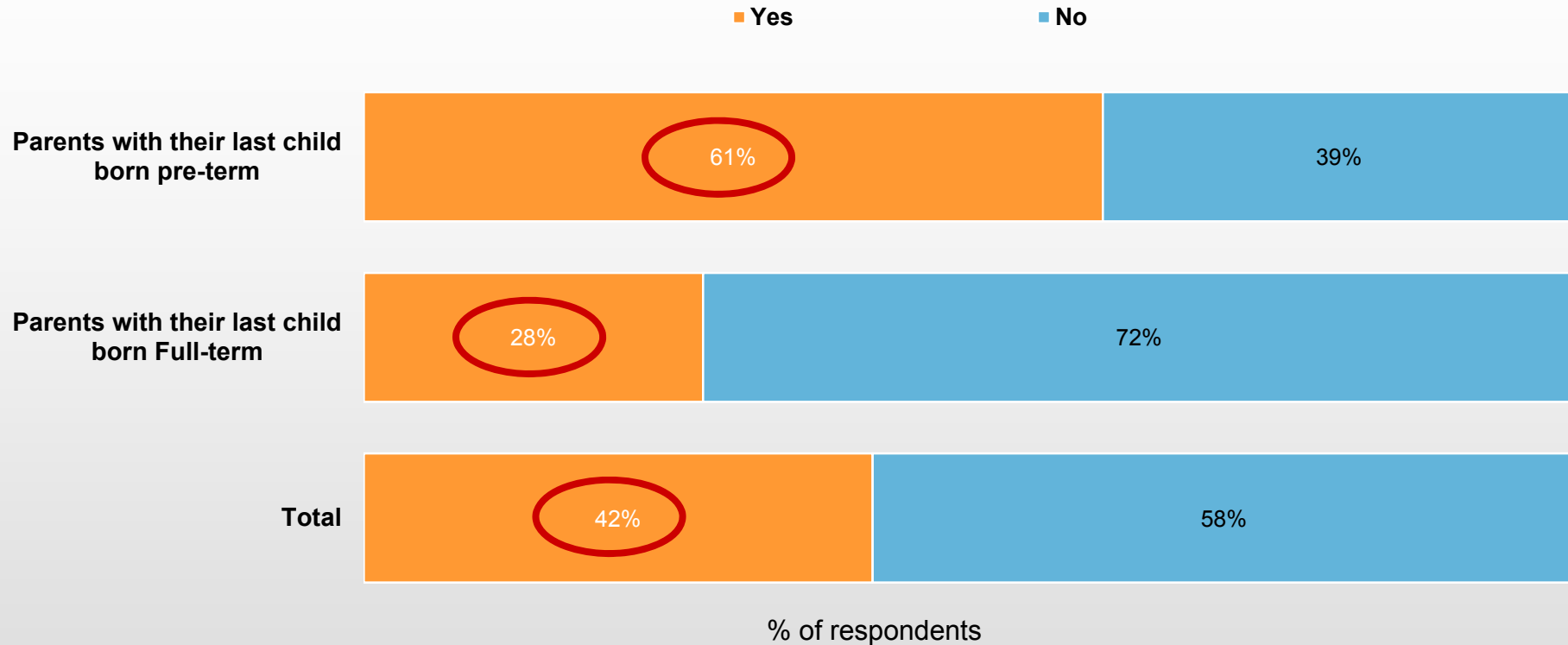


- Overall, over 8 out of 10 respondents think that pre-mature infants are more susceptible to respiratory infections.

Base: 135 respondents
Q 27 Do you think that premature infants are more susceptible to respiratory infections than full-term infants?



Has the parent given or sought information for preventing respiratory infections in infants?



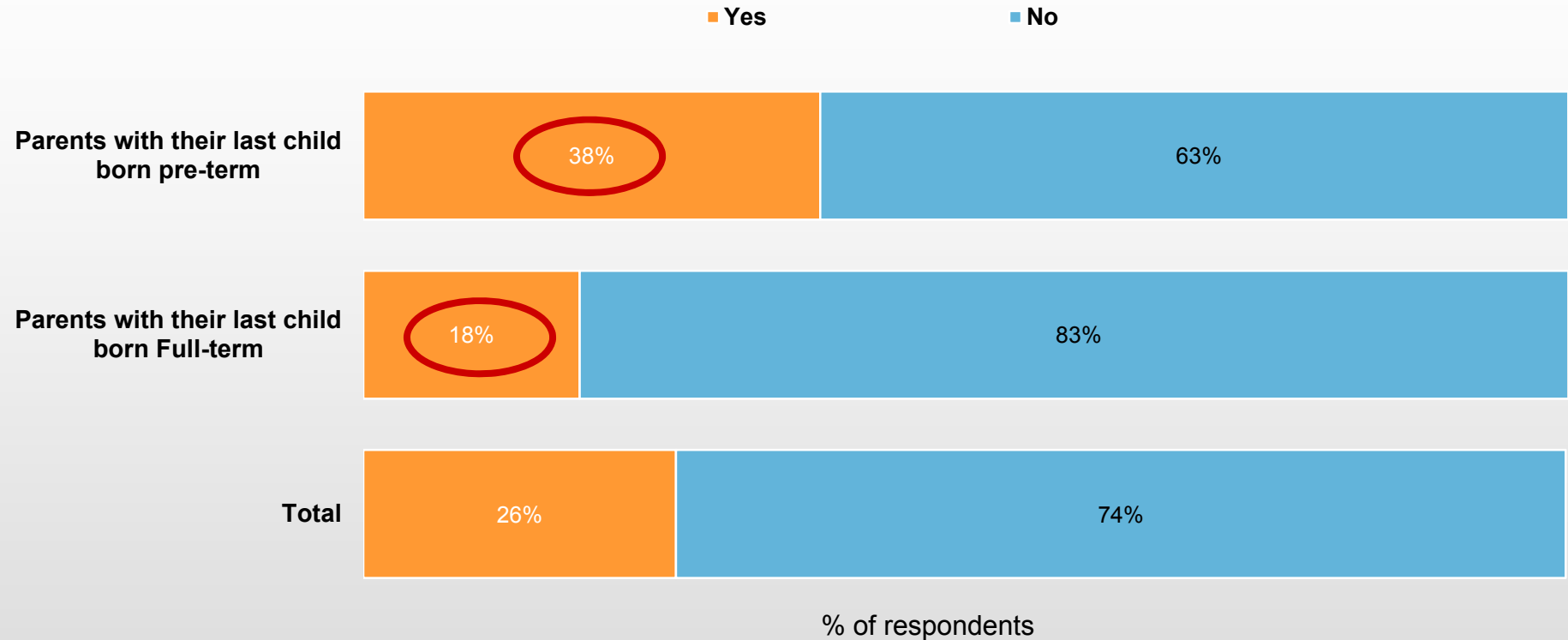
- Overall, over 4 out of 10 respondents were given or sought information for preventing respiratory infections. The level between the parents of pre-term (61%) and full-term (28%) children are very different.

Base: 135 respondents

Q 28 Have you ever been given or sought information for preventing respiratory infections in your infant?



Has the baby of the respondent developed any severe respiratory infection in the last 1 year?

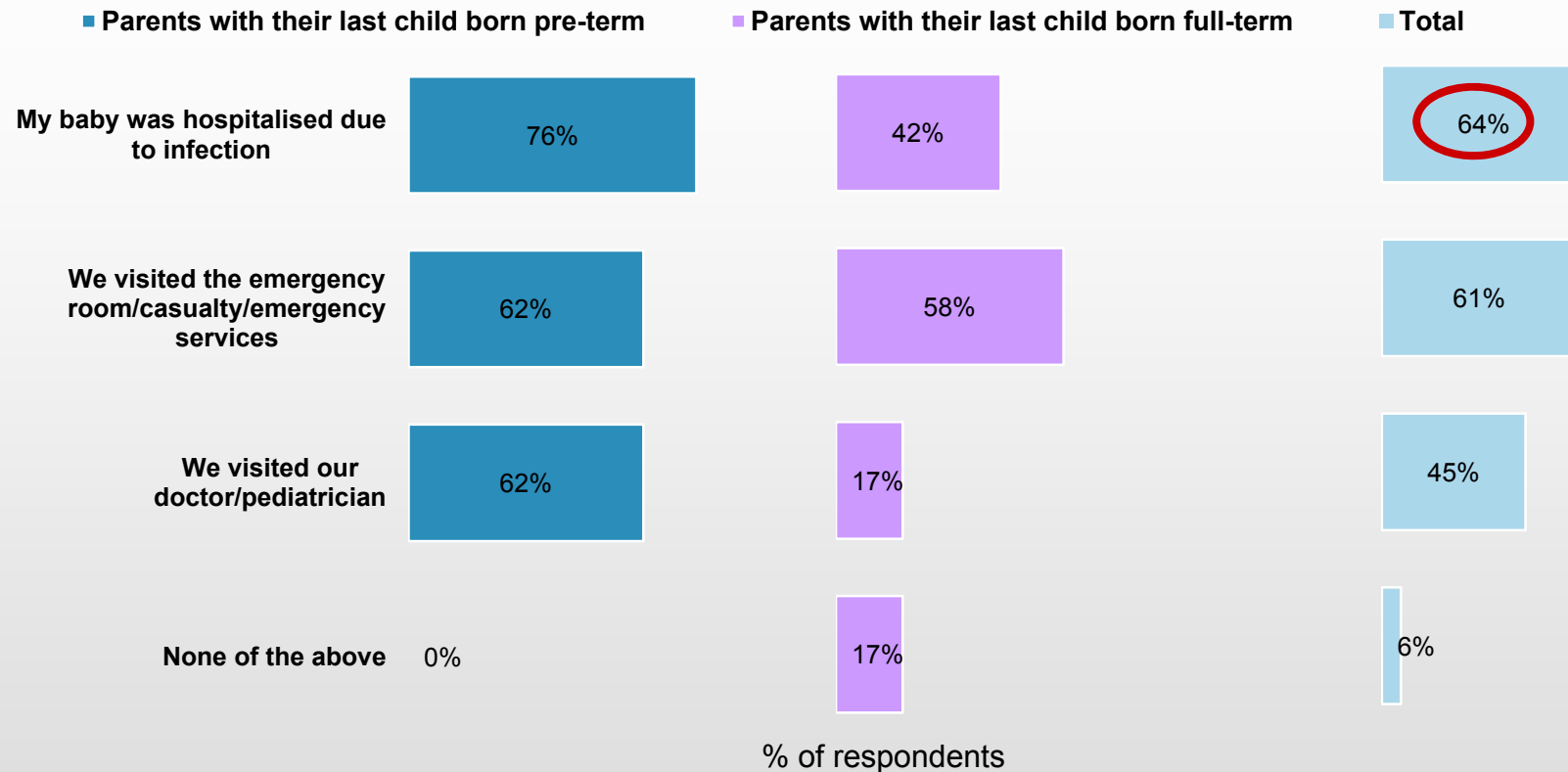


▪ Nearly 1 out of 5 parents whose last child was full-term advised that their baby developed a severe respiratory infection in the last 1 year. The rate advised by parents of pre-term babies is twice as high at 38%.

Base: 136 respondents
Q 29 Did your baby develop any severe respiratory infection in the last 1 year?



Events resulting from the respiratory infection

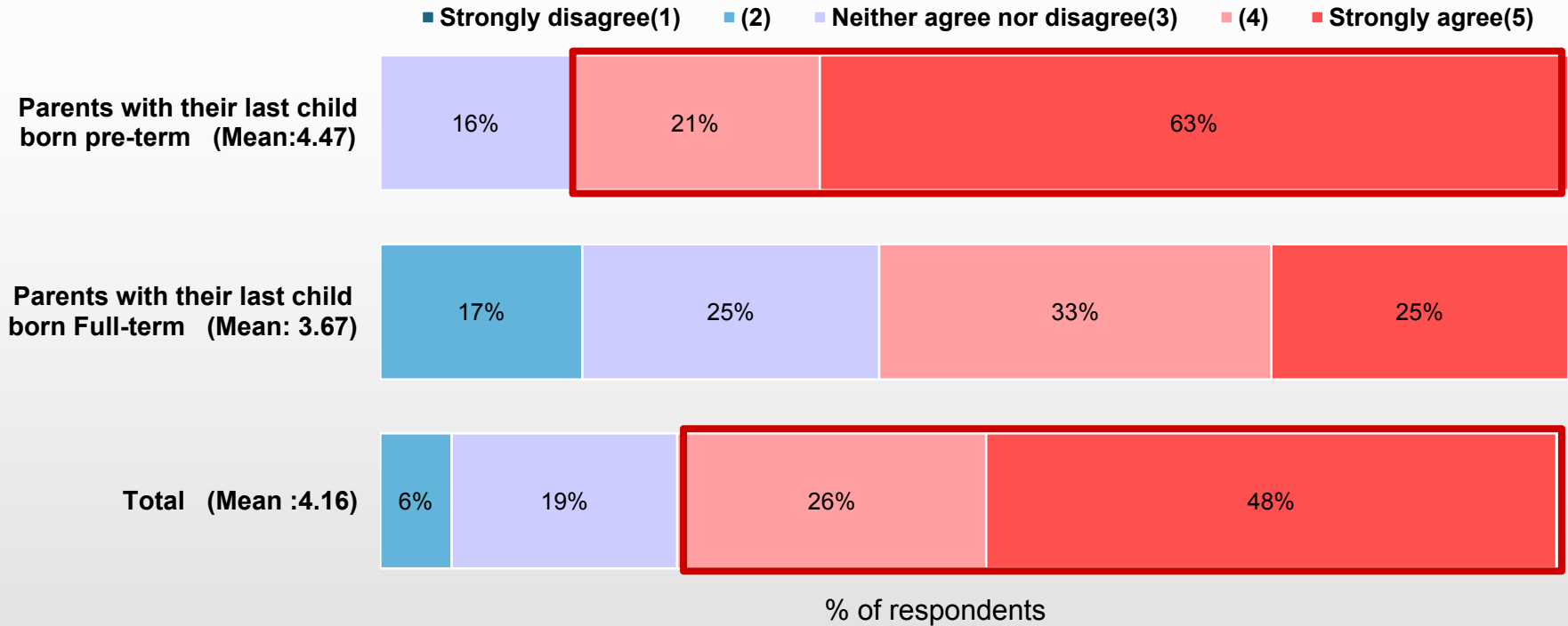


- Overall nearly 2/3 where their baby developed a severe respiratory infection indicated their baby was hospitalised due to infection, 6 out of 10 visited the emergency room/casualty/emergency services.

Base: 33 respondents
Q. 30 As a result, which of the following events occurred?



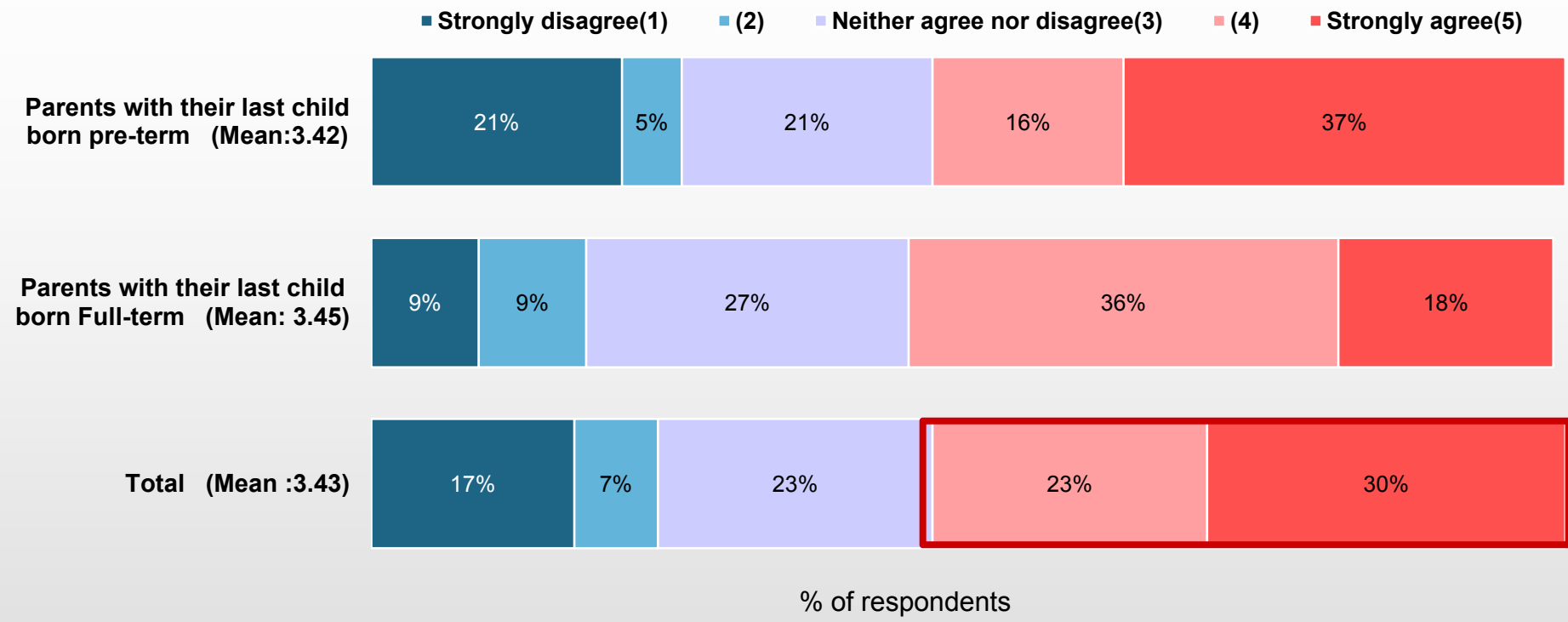
The respiratory infection affected the parents emotionally



▪ Nearly two thirds of parents whose baby had developed a severe respiratory infection indicated that their baby was hospitalised as a result. Over 60% visited the emergency room/casualty/emergency services as a result of the infection.

Base: 31 respondents
Q 31 To what level do you agree with the following statements:
The respiratory infection and following events affected me and my spouse emotionally.
Please indicate on a scale of 1 to 5

abbvie The respiratory infection affected the parents financially



▪ Overall just over half of respondents advised that the infection affected them financially.

Base: 30 respondents
 Q 31 To what level do you agree with the following statements:
 The respiratory infection and following events affected me and my spouse financially.
 Please indicate on a scale of 1 to 5

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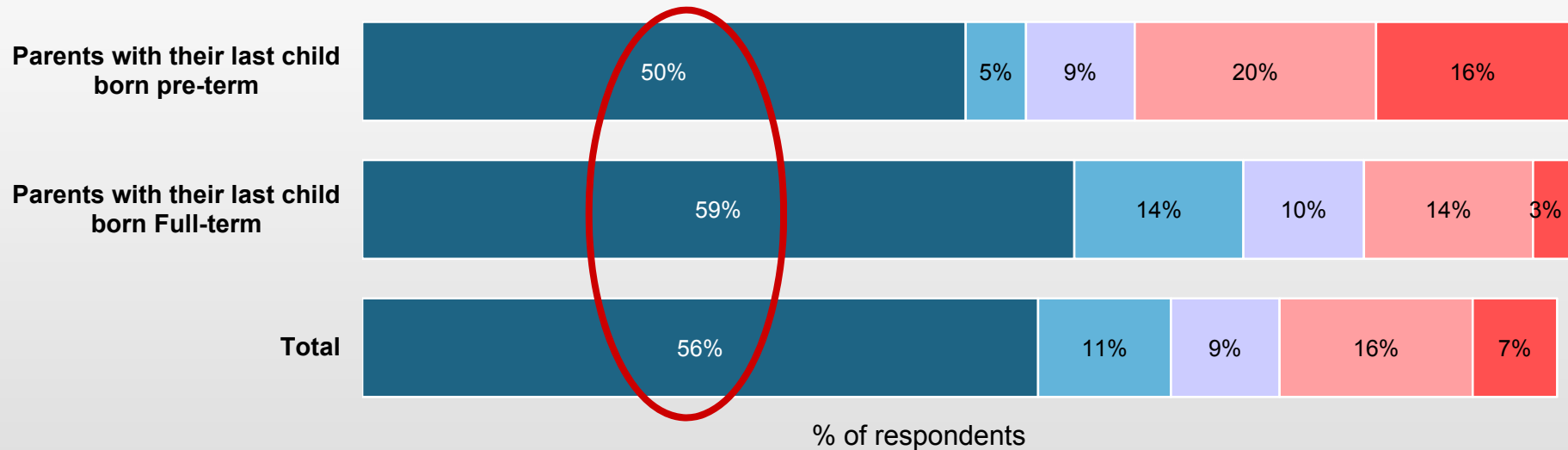
Section 6

The Future



Advice to give to a parent that may be at risk of having a premature baby

- Ask as many questions from medical professionals as possible
- Don't worry – the health outlook will be positive with the right treatment
- Lean on family/friends for support
- Don't blame yourself for the prematurity
- Seek advice parents of other premature children



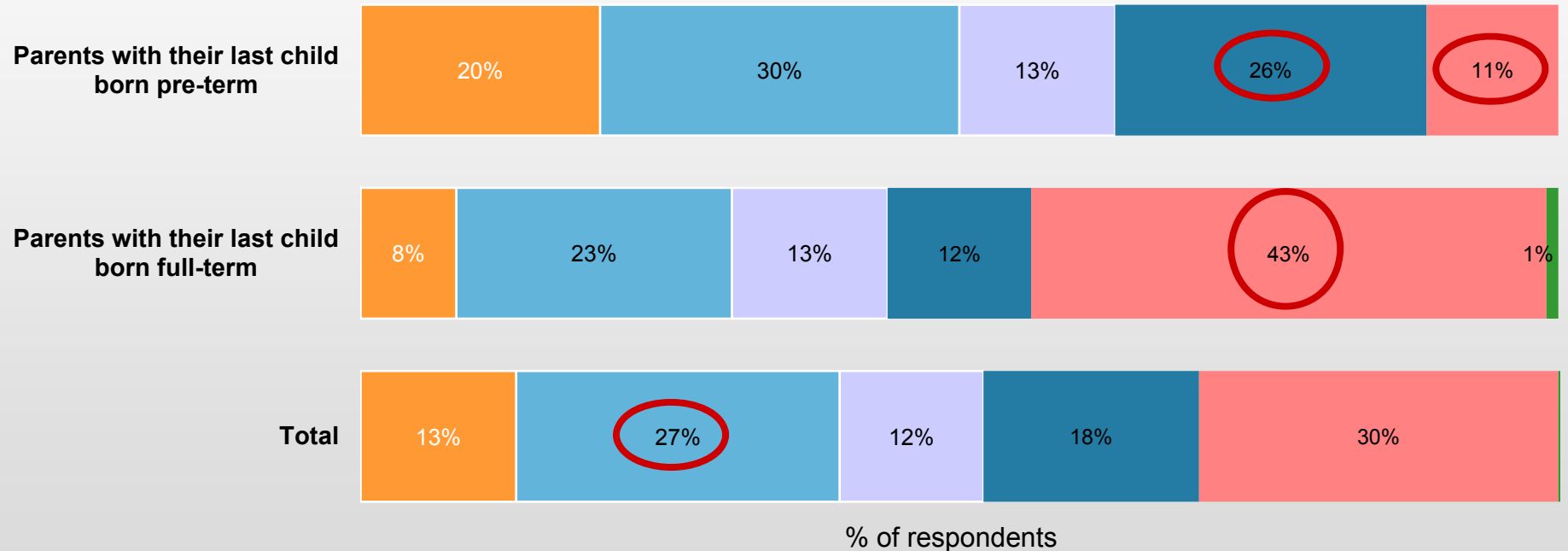
- Advice suggested for parents that may be at risk of having a premature baby is to ask as many questions as possible of their medical professionals.

Base: 149 respondents

Q 32 What piece of advice would you give a parent that may be at risk of having a premature baby? (CHOOSE ONE)

Worries about the future of infant

- Lagging behind in physical development compared to other children, e.g. height
- Long-term health complications
- Lagging behind in emotional development compared to other children, e.g. how they interact with other children or people
- Lagging behind in intellectual development compared to other children, e.g. schoolwork and ability to learn
- No worries, they catch up and become normal
- Worry that the infant will have an early death



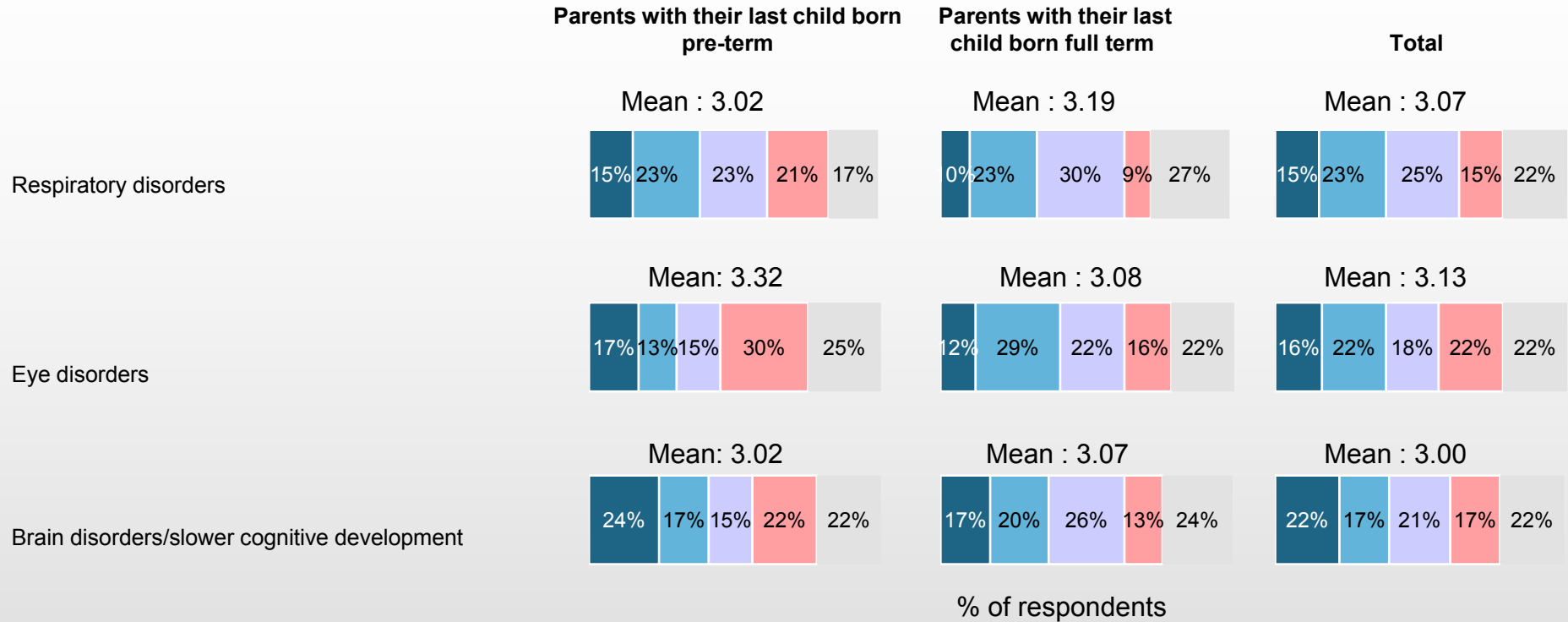
■ Parents of full-term children are less worried. Overall their main concern is over long-term health complications. For parents whose last child was pre-term they also have concerns over 'lagging behind in intellectual development compared to other children.'

Base: 145 respondents
 Q 33 What worries you the most about the future of your infant? (CHOOSE ONE)



Long-term Health Complications Worries

■ Not at all concerned(1) ■ 2 ■ Moderately concerned(3) ■ 4 ■ Very concerned

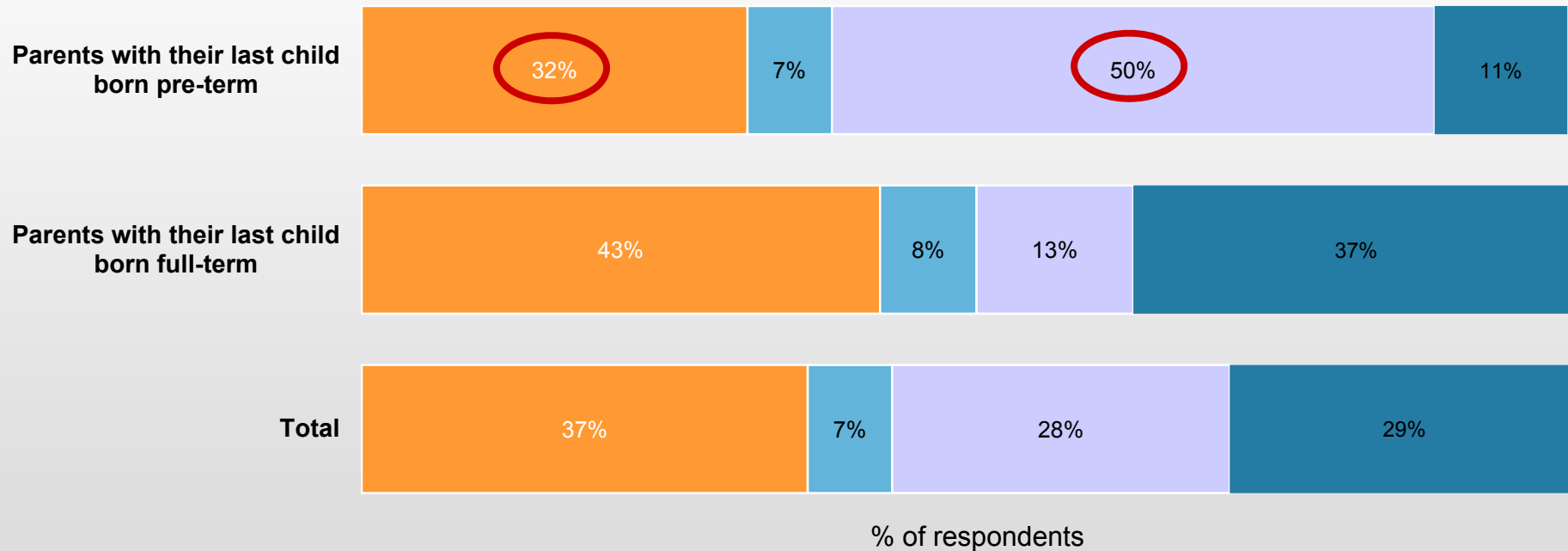


■ There's little difference in the levels of concern among the groups. Parents of pre-term are more concerned about eye-disorders.

Base: 143 respondents
Q.34 What types of long-term health complications are you mostly worried about? Please indicate your level of concern on a scale of 1 to 5

Has having a premature infant changed views of having more children in the future?

- Yes, having a preterm infant has made me LESS likely to have more children
- Yes, having a preterm infant has made me MORE likely to have more children
- Having a preterm infant has not changed my views on having more children
- Don't know

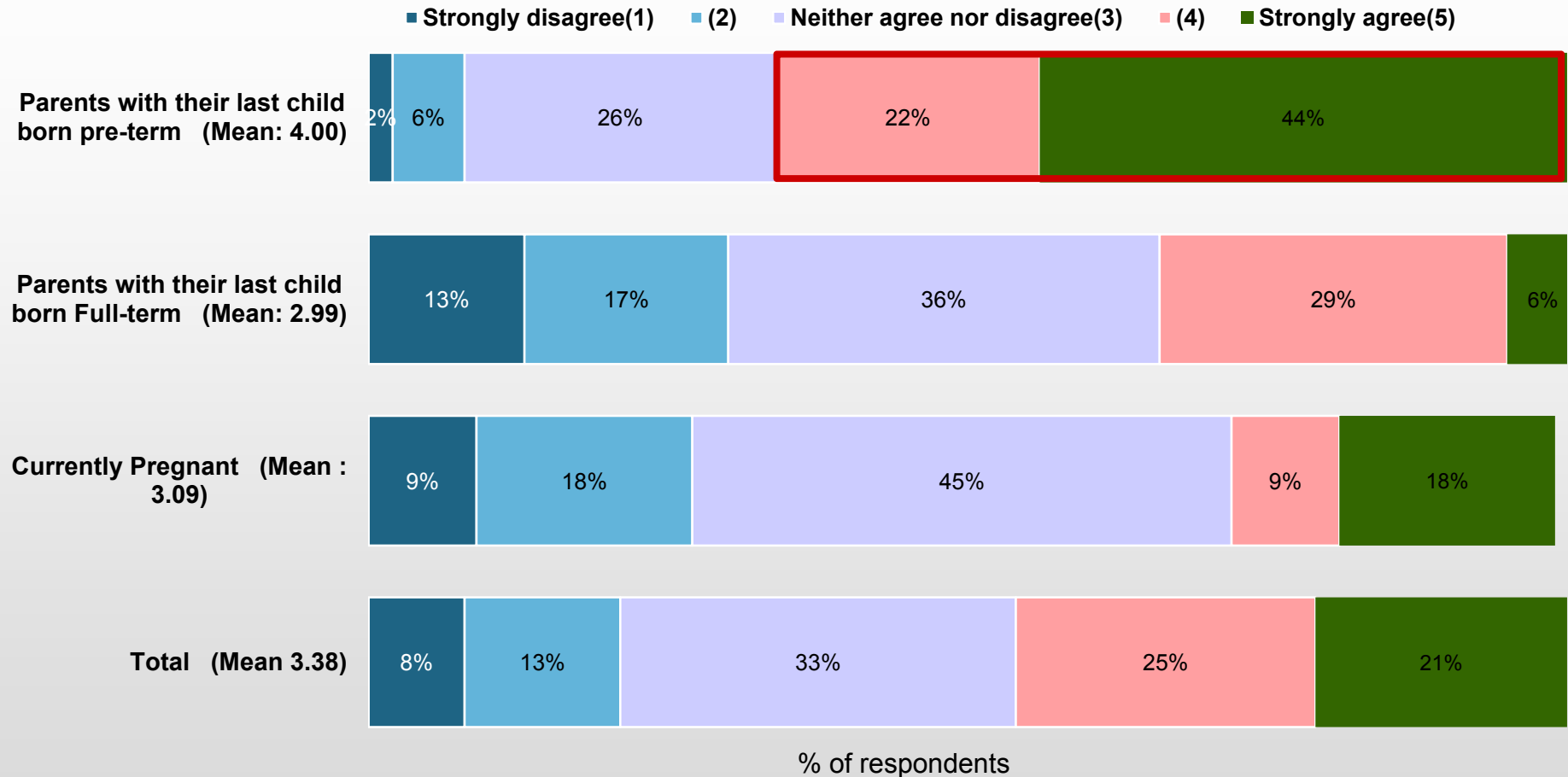


▪ Half of parents whose last child was pre-term say their view has not changed on having more children. Nearly a third of them say it has made them less likely to have more children in the future.

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Section 7
Knowledge and Information Received

abbvie Adequate level of knowledge of the risks associated with prematurity



- Parents whose last child was pr-term are more in agreement with the statement than the other groups. INHA respondents are also in agreement.

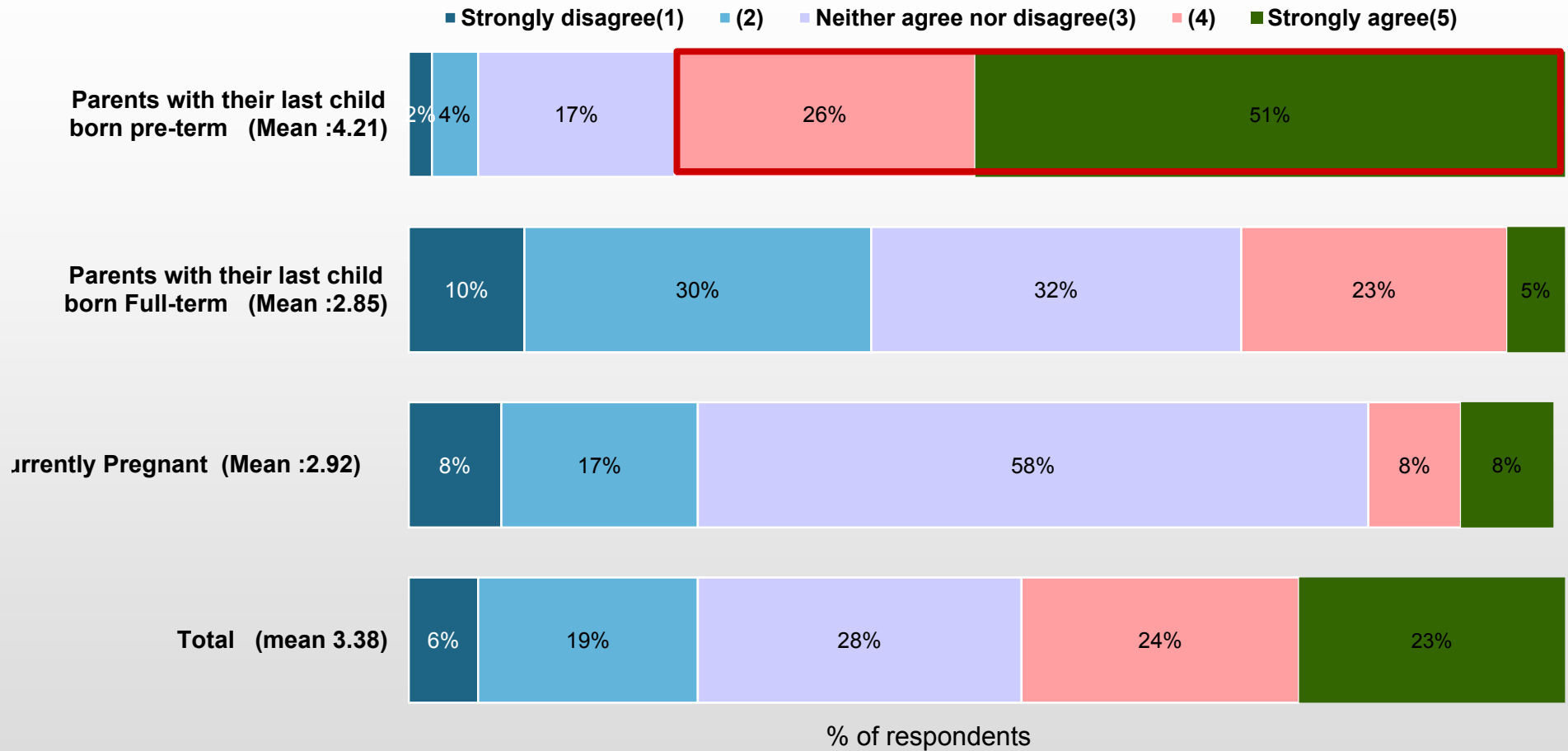
Base: 134 respondents

Q 36 Please indicate your level of agreement on each of the following statements. Please use a scale of 1 to 5.

1. I have an adequate level of knowledge of the risks associated with prematurity



Good level of knowledge of the complications associated with prematurity



- Parents whose last child was pre-term are in more agreement with the statement than the other groups. INHA respondents are also in agreement.

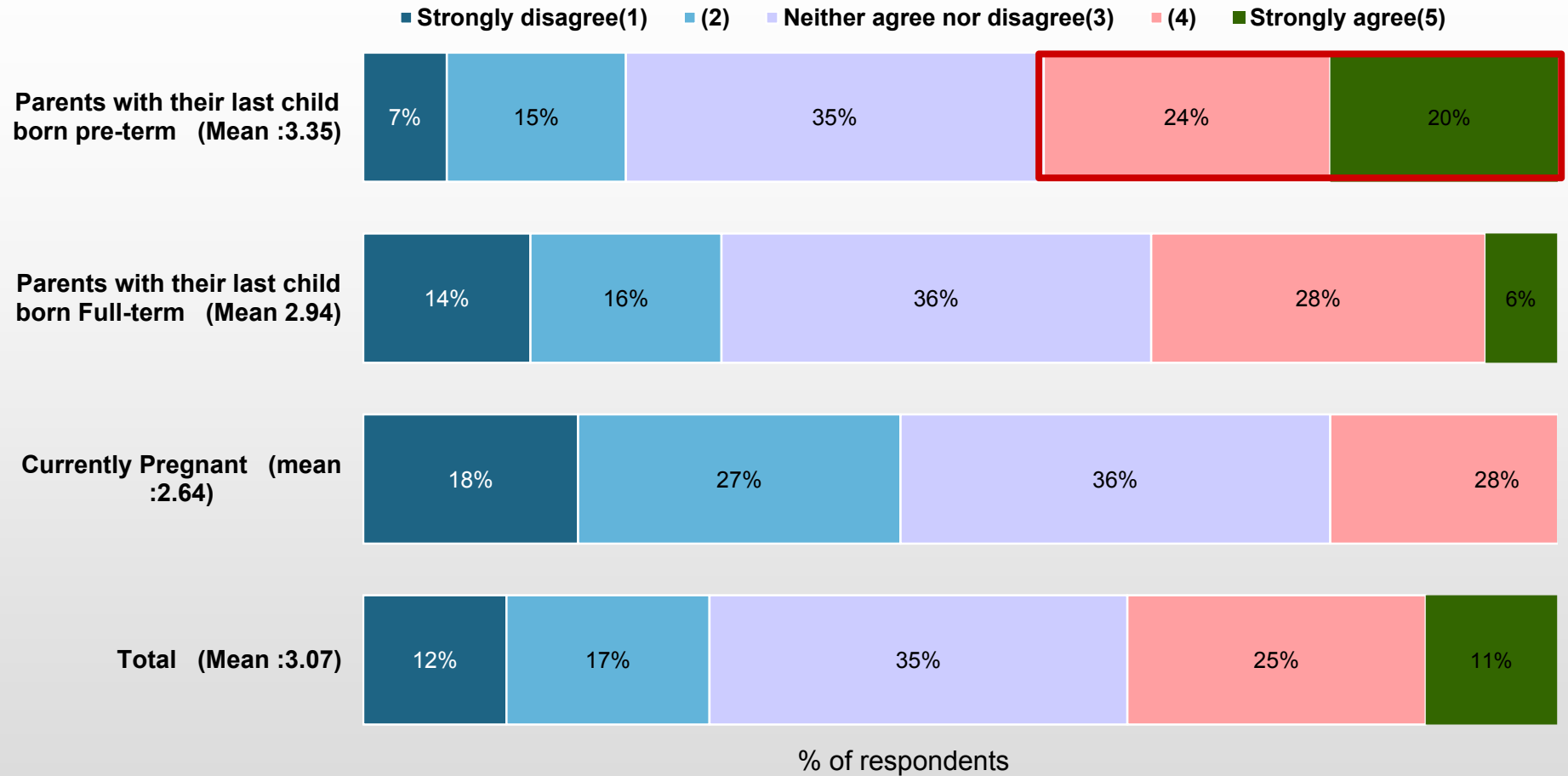
Base: 139 respondents

Q 36 Please indicate your level of agreement on each of the following statements. Please use a scale of 1 to 5.

2. I have a good level of knowledge of the complications associated with prematurity



Healthcare provider has provided the appropriate level of information about premature birth



Although parents whose last child was pre-term (and INHA respondents) are in more agreement with the statement than the other groups, their mean score compared to earlier statements is lower indicating a **gap** exists in the information parents have, and what they believe their healthcare provider could provide.

Base: 127 respondents
Q 36 Please indicate your level of agreement on each of the following statements. Please use a scale of 1 to 5.
3. My healthcare provider has provided me with the appropriate level of information about premature birth



Interested in topics about premature birth

	Parents with their last child born pre-term	Parents with their last child born Full term	Currently Pregnant	Total
Potential health complications of a premature infant	73%	52%	46%	60%
Recommended doctor / nurse follow-ups	52%	39%	54%	46%
Emotional and psychological support groups and / or counseling	61%	34%	23%	44%
Health risk / impact on the mother of a premature infant	36%	25%	23%	30%
Information on the potential financial impact of having a pre-mature infant	36%	20%	23%	27%
Navigating childcare/ daycare for a premature infant	30%	24%	8%	25%
No information on premature births	%	19%	31%	13%

- Overall over half of respondents indicated they are most interested in knowing more about 'potential health complications of a premature infant'. For parents whose last child was pre-term, three quarters are interested in knowing more.
- For those currently pregnant, they are most interested in knowing more about 'Recommended doctor/nurse follow-ups.'

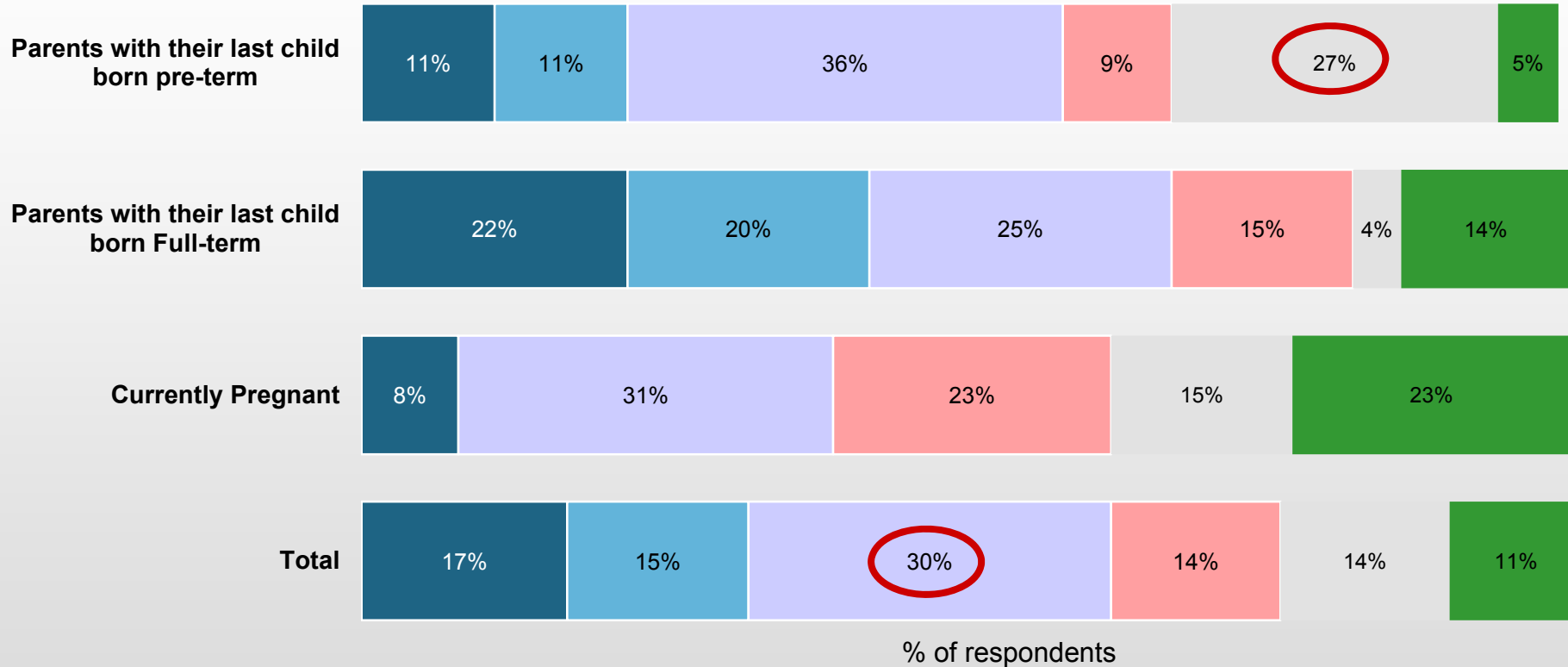
Base: 149 respondents

Q. 36/4. What topics concerning premature births, if any, were you/are you interested in knowing more about? What topics about premature births are you more interested in learning about (CHOOSE MULTIPLE)



Expect to receive information on prematurity

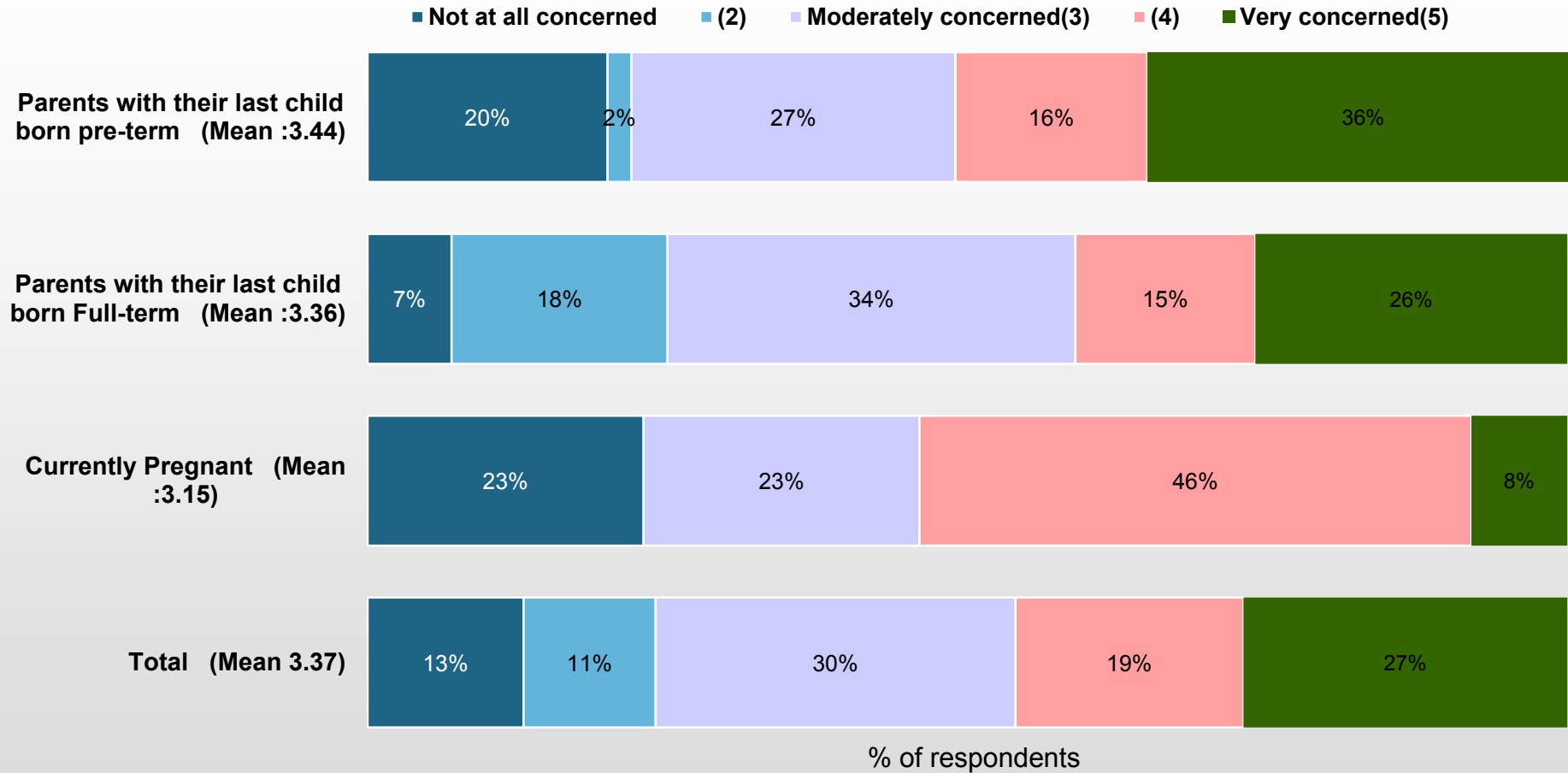
- Before pregnancy
- Up to the 1st trimester
- During the 2nd trimester
- During the 3rd trimester
- After giving birth
- I don't expect to receive information



- Overall, 3 out of 10 respondents expect information in prematurity during the 2nd trimester. For parents whose last child was pre-term just over quarter expect information after giving birth.



Concern about the possibility of having a premature baby



Overall the level of concern show that respondents are moderately concerned. Parents whose last child was pre-term are more concerned than the other groups.

Base: 132 respondents
Q 36 /6. How concerned are you about the possibility of having a premature baby? Please indicate your level of concern on a scale of 1 to 5