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REGIONAL OFFICE FOR EUROPE

EUROPEAN LONGITUDINAL STUDY OF PREGNANCY AND CHILDHOOD (ELSPAC)

Report on a Meeting of Principal Investigators

Bristol, United Kingdom
23–29 June 1997

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1998

EUR/HFA target 7

TARGET 7

HEALTH OF CHILDREN AND YOUNG PEOPLE

By the year 2000, the health of all children and young people should be improved, giving them the opportunity to grow and develop to their full physical, mental and social potential.

ABSTRACT

The European Longitudinal Study of Pregnancy and Childhood (ELSPAC) was initiated by the Regional Office in 1985 to improve epidemiological knowledge of factors influencing children's health in European countries. It is designed to cover various aspects of the life and environment of pregnant women and children. The 1997 meeting was devoted to planning examinations and questionnaires for children in the study aged 7 years and, following the recent publication of the first ELSPAC book, the further planning of the next three books. Progress reports from participating countries were reviewed and discussed. One study centre in Ukraine had stopped collecting data, and Greece was not represented owing to lack of funds and the unlikelihood of it being able to carry out the 7-year follow-up. There were now 11 study centres collecting data in 6 countries and areas (Czech Republic, Isle of Man, Russian Federation, Slovakia, Ukraine and United Kingdom). The participants agreed that the next meeting should focus on the publication of the three books as planned, and to report on progress with the three books as planned, and to report on progress with the 7-year assessments.

Keywords

LONGITUDINAL STUDIES
PREGNANCY
CHILD HEALTH
CZECH REPUBLIC
ISLE OF MAN
RUSSIAN FEDERATION
SLOVAKIA
UNITED KINGDOM
UKRAINE

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CONTENTS

Page

Introduction 1

Country reports 1

- Czech Republic 1
- Greece 1
- Isle of Man 2
- Russian Federation 2
- Slovakia 3
- Ukraine 3
- United Kingdom 4

Management of the Study 4

- Back translations 4
- Coding and editing 6
- Data received in Bristol 7

ELSPAC protocol 7

Questionnaires at 7 years 7

Assessments at 7 years 7

- Mandatory assessments 7
- Optional items 8
- Practical arrangements 8
- Timing 8
- Inclusion criteria 9

Publications and authorship 10

- Publications 10
- Authorship 10
- Rules for comparative analyses 10
- Planned ELSPAC books 11

Report from the Coordinating and Executive Committee 13

Other matters 14

The 1998 meeting 14

Annex 1 Participants 15

Annex 2 Details of proposed tests at 7 years 17

INTRODUCTION

The 1997 meeting of the ELSPAC (European Longitudinal Study of Pregnancy & Childhood) principal investigators was devoted mainly to the planning of the 7-year examinations and questionnaires. Country reports were discussed at the preliminary session and are summarised below. The meeting was attended by 12 participants from 5 countries (see Annex 1). Apologies were received from Dr Mangiaterra from WHO, Professor Eleni Adam and Professor Thalia Dragonas from Greece, and Professor Stejskal from the Czech Republic. The meeting regretted that Dr Vivianna Mangiaterra was unable to attend.

This meeting congratulated Dr Ilona Koupilova on both achieving a PhD in Uppsala and obtaining the prestigious lectureship at the London School of Hygiene and Tropical Medicine.

COUNTRY REPORTS

Czech Republic

Dr Kukla reminded the meeting that the birth cohort dates were from 1 March 1991 until 30 June 1992. The 5-year follow-up sweep was just ending. He reported the success of sending good wishes 3 weeks before the child's birthday and having an art competition. The 5-year questionnaire was sent in two parts, but there was a discussion as to whether there was a need for more medical data than on the questionnaire. A major effort was being made to try and find all hospital admissions for these children, and it was hoped that when there was a new director of the Children's Hospital this might become easier.

He felt that it was also important to get information on outpatients and was preparing a short questionnaire. The collection of data on stillbirths and infant deaths was proceeding well.

Dr Kukla had started a newsletter for the medical professions and a third newsletter for parents. In the last year he had appeared on Brno radio at least seven times with an interview of an hour.

Funding for the Czech project depends on a grant from the Ministry of Health. It had received a grant for nine years in all, and consequently there are just two years left. A new grant must be prepared next year to cover the study from the year 2000.

One of the major problems that Dr Kukla had had during the previous year was the theft of his portable computer. This had been a major drawback to him as it contained a number of documents on which he was working, although it had not affected the integrity of the statistical data from Czech Republic.

One of the important achievements of the study had been collaboration with the medical faculty for the analysis of heavy metals in the placenta.

Greece

Dr Adam sent word that her funding had been substantially cut and unfortunately she saw no way in which she would be able to carry out the 7-year assessment.

Isle of Man

Dr Goodfellow reported on the important progress being made in raising the profile of the study on the island. A committee had been formed to help raise money specifically for the project, and she had already identified and been offered the antenatal clinic accommodation in the maternity hospital in which to do the 7-year assessments.

She reported that the major loss of response in the island had been related to the lack of cooperation from the senior health visitor on the island who had forbidden workers to help with the study. Nevertheless the efforts being made to persuade mothers to rejoin the study was showing promise, and new publicity campaigns for the whole island were being very productive.

Fund-raising efforts on the island were targeted on people who would either pay for one child to undergo all tests (estimated at £120) or for the funding of a whole test (£5000).

Dr Goodfellow was forging a useful academic link with Liverpool University, particularly the Psychology Department at Chester College. This was thought to be very important in helping to recruit appropriately qualified staff for the 7-year follow-up.

Russian Federation

Professor Rimma Ignatyeva and Dr Vadim Kagramanov reported on the progress of the ELSPAC study in the Russian Federation. On the whole there had been some achievements during the 10 months since the group had last met. During 1996, the 3-year questionnaires had been completed, although the health reports had not yet been done.

The Russians had decided that the health reports could wait and had expanded data collection so that different blocks of health reports could be completed at different times. They thought they could do this retrospectively at age 7. The advantage of the study in the Russian Federation is that there is a long history of childhood developmental tests being undertaken with results recorded, but in order to complete the health reports, it will be important to pay people to complete the questionnaires. Unfortunately, the local financial support they had had earlier from Yaroslavl was not given in 1996/1997.

During the previous 3–4 years, political changes in the Russian Federation had resulted in the introduction of medical insurance with a very short list of free procedures and no free preventive procedures. Consequently, the 7-year follow-up assessments could not be fitted into the normal health care system and would have to be paid for separately.

The good news was that within the Semashko Institute a small seven-person unit was now mainly devoted to ELSPAC. The basic salaries of this team were paid by the Academy of Medical Science, but that did not cover travel, coding and keying, using people outside the team.

Nevertheless, data preparation had been proceeding well and there were now 1694 delivery questionnaires keyed, 1018 6-week sets of questionnaires and 1208 neonatal admissions (for 791 children). The aim now was to concentrate on the antenatal questionnaires so that they too would comprise over 1000 sets. Ideally, the antenatal and 6-week questionnaires for the 1694 births for which delivery questionnaires had been obtained would also be obtained.

Professor Ignatyeva reported that she had been attempting to get funding for the ELSPAC book to be published in Russian but had not had any luck so far. She hoped that the British Council might help in publishing the book. However, the Russian representative of the British Council had said that he might be able to pay for training within the ELSPAC programme.

Professor Ignatyeva reported that the seven staff in her unit comprised the only international project of the Russian Academy of Medical Sciences.

With regard to the 7-year questionnaire, Professor Ignatyeva had successfully identified a group who went from school to school, training children for family life. This organization, which was run by a colonel, was happy to collaborate with the ELSPAC team. It was planned to equip the group's bus with the equipment needed for the 7-year follow-up assessments, and Professor Ignatyeva would be able to fit into the existing schedule for this educational group.

There are two options for training for the 7-year assessments: (a) personnel go to Bristol for training in validity and compatibility, or (b) ELSPAC personnel visit participating countries.

Professor Ignatyeva said that with the current finances they are able to carry out the existing study but the 7-year study was going to be extremely difficult. Printing is prohibitively expensive and the medical profession is underpaid, but if the study can pay basic salaries it would be possible to make progress.

It was important that Professor Jean Golding write a letter setting out the cost of the different items of equipment that will be needed at 7.

Professor Ignatyeva was congratulated on the progress made since the last meeting.

Slovakia

As of September 1996, the 18-month questionnaires had been coded and keyed. Delivery questionnaires had been coded and keyed and should be finished by the end of September 1997. Sending questionnaires to parents, even with two reminders and a direct contact, had resulted in promises but not realisation of completed questionnaires. Nevertheless, the postnatal response had been much better than the antenatal response.

Advantages to being in the study include swimming courses for the children and (for those who need it) stays in high mountain areas for both parents and children. The study is able to provide advantageous insurance and stickers as a gift to the participants.

Ukraine

Professor Shkiriak-Nyzhnyk reported that despite the lack of funds available when the 1996 report was compiled, the study in Ukraine had continued to do well. The project was continuing but with five sites now collecting data instead of the original six: it had been decided not to continue work at the Kiev Right Bank site and as yet no data collected from that site have been coded or keyed. With the help of funding from the NIEHS in the USA, it has, however, been possible to code and key all the questionnaires collected up to and including the 6 weeks' postnatal questionnaire for the Kiev Left Bank and Dniprodzerzhynsk sites. The textual responses for all these questionnaires have also been completely coded and keyed. Professor Ruth Little (a senior visiting American epidemiologist) had been instrumental in helping to set

up a large and detailed quality and logical edit of the numeric and text coding, in particular of the delivery data. As a result, the data collected from the Dniprodzerzhynsk and Kiev Left Bank sites are deemed to be of a very high standard. Extensive quality checking had also been carried out to ensure that every study subject and all her questionnaires had been allocated the correct id. An archive was set up to store and inventory the questionnaires. They are now stored in number order and by site. The coding, keying and editing operation was supervised by Louise Khmara from the Bristol Office until March 1997 under the direction of Susan Monaghan. It was now felt that a sound infrastructure, good computing facilities and a core of well trained and disciplined staff had been established and that the Ukrainian study was well able to continue the good work it had started without such close supervision from the Bristol office.

Funding has also started to come in for coding and keying data collected at the other sites. The antenatal questionnaires from Ivano-Frankivsk have been coded and keyed. However, further funding has yet to be raised in order to complete the quality checking measures also required.

Substantial funding has also been raised from the Environmental Protection Agency in the USA. This will help to pay for the collection and processing of the child questionnaire to be administered at 3 years.

Ukraine is hoping to be able to do examinations of the thyroid by ultrasound.

United Kingdom

Mr Hugh Simmons (the manager at the Avon centre) reported that response rates were still good, and strenuous efforts were being made to contact participants who were defaulting on sending back their questionnaires. Newsletters were being sent to parents three times a year. The involvement of the study children was being encouraged with simple questionnaires asking for colouring and drawing. This had proved very popular.

All questionnaires received during the year are coded during the university vacations in the summer by selected students. In 1997, this amounted to 26 000 questionnaires concerning the parents and the study child. The long process of abstracting information for the delivery questionnaires had continued and approximately 5000 had so far been completed by a specially trained team. In like manner the initial completion of the neonatal admissions questionnaires had now been finished. Work was proceeding on coding and entering on to the computer the text answers.

Preparations for the 7-year assessments were going ahead and funding being sought. Liaison with schools, their head teachers and the education authorities was being intensified.

Management of the Study

Back translations

The Coordinating Centre continued to be worried at the failure of centres to carry out and clear back translations before printing questionnaires. Dr Kukla pointed out that this was often difficult because of the relatively short length of time between receipt of the agreed English version and the translation and printing of the country's own version. By planning now for the 7-year questionnaires it should be possible to ensure complete comparability at this stage.

Meanwhile, it was important that all cross-cultural comparisons take account of the possible differences in translation between centres.

Table 1. Status of self-completion questionnaires received

County/Centre	Antenatal	6 weeks	6 months	18 months	3 years	5 years
Czech Republic						
Brno	3 855[a]	3 901[a]	3 630[a]	3 231[b]	3 149[b]	2 632[a]
Znojmo	1 319[a]	1 214[a]	1 000[a]	376[a]	501[b]	575[a]
Greece						
Athens	4 834[b]	1 850[b]	1 574[b]	850[b]	NC	NC
Isle of Man	1 062[e]	848[e]	720[e]	719[b]	614[a]	536[e]
Russian Federation						
Yaroslavl	5 336[c]	4 387[d]	3 856[c]	2 830[d]	3 838[d]	NC
Slovakia	1 343[a]	1 783[b]	1 790[a]	1 522[d]	671[a]	–
Ukraine						
L bank Kiev	1 113[b]	420[b]	179[e]	NC	–	–
R bank Kiev	740[e]	100[e]	30[e]	NC	–	–
Dniprodzerzhynsk	2 056[e]	978[b]	305[e]	NC	–	–
Mariupol	894[e]	397[e]	60[e]	NC	–	–
Ivano-Frankivsk	1 706[e]	694[e]	60[e]	NC	–	–
Krasnyj-Louch	1 284[e]	100[e]	–	NC	–	–
United Kingdom						
Avon	13 268[a]	12 394[a]	11 502[b]	11 142[b]	9 500[e]	–

NC not collected; [a] keyed and edited; [b] keyed, not edited; [c] coded, not fully keyed; [d] collected, not yet fully coded; [e] questionnaires still being returned.

Table 2. Medical records

Country/Centre	Eligible deliveries	Delivery questionnaire	Neonatal admissions questionnaire	Death questionnaire	6-month health report	18-month health report	3-year health report
Czech Republic							
Brno	–	5541[a]	641[a]	71	5370[b]	4998[d]	4518[d]
Znojmo	–	1801[a]	95[a]	–	1677[b]	1220[d]	990[d]
Greece							
Athens	6441	6441	–	–	–	–	–
Isle of Man	1303	1318[e]	125[c]	9[d]	955[d]	NC	NC
Russian Federation							
Yaroslavl	6093	5913[d]	1208	129[a]	3856[d]	2830[d]	NC
Slovakia	3121	3005[a]	211[a]	–	2293[d]	1525[d]	–
Ukraine							
L bank Kiev	1104	795[e]	219[e]	12[e]	–	–	–
R bank Kiev	830	500[e]	–	–	200[e]	–	–
Dniprodzerzhynsk	2055	1572[e]	402[e]	45[e]	–	–	–
Mariupol	1137	1070[e]	161[e]	13[e]	650[e]	–	–
Ivano-Frankivsk	–	1539[e]	99[e]	16[e]	200[e]	–	–
Krasnyj-Louch	1560	1100[e]	95[e]	15[e]	700[e]	–	–
United Kingdom							
Avon	?	3500[e]	925[e]	229[c]	–	–	–

NC not collected; [a] keyed and edited; [b] keyed, not edited; [c] coded, not fully keyed; [d] collected, not yet fully coded; [e] questionnaires still being returned.

A number of points and misunderstandings were clarified. Back translations did not need to be in perfect English and it was not necessary for study directors to check and annotate them. This would be done by the Bristol office, who would identify any problem areas and discuss them with the relevant study director.

Table 3. Back-translations received in the Bristol office

		Czech Republic and Slovakia	Russian Federation	Ukraine	Greece
Self-completion questionnaires					
Antenatal	Mother	+	+	+	+
	Partner	+	+	+	–
6 week	Mother	+	+	+	–
	Partner	+	+	+	–
	Child	+	+	+	–
6 month	Mother	+	–	–	
	Partner	–	+	–	–
	Child	–	+	–	–
18 month	Mother	–	+	+	–
	Partner	–	+	+	–
	Child	–	+	+	–
3 year	Mother	–	+	+	N
	Partner	–	+	+	N
	Child	–	+	+	N
5 year	Mother	–	N	–	N
	Partner	–	N	–	N
	Child	–	N	–	N
Clinical records					
Delivery		+	+	+	–
Neonatal admissions		+	+	+	–
Death questionnaire		+	+	+	–
Hospital admissions		+	–	–	–
6 month health report		–	+	–	–
18 month health report		–	+	–	–
3 year health report		+	–	+	–
5 year health report		–	–	–	–

+ back-translation received; – no back-translation received; N questionnaire not being administered.

Coding and editing

It was important that each study centre carried out the coding and editing instructions as outlined in the coloured sheets attached to each of the original questionnaires, before the data were used or transferred to the Bristol office.

The Czech Republic reported that they were using their own software to do this and would send their coding and editing instructions to Bristol.

Professor Ignatyeva said that data from the Russian study were being cleaned at the coding stage. A supervisor checked a sample of coding and keying outputs. She thought there would be no problem, although this would need to be carefully checked.

Greece reported that because of poor keying there were 60 records with duplicate numbers which had to be excluded. This highlighted the use of a check digit on each record. [A check digit is a number or letter added to each study number which with a simple software programme will check whether the study number is likely to have been keyed accurately (contact Hugh Simmons for further details).] This system had been used successfully in Avon.

Data received in Bristol

Keyed and edited data have been deposited in Bristol for the Czech Republic, Greece, Isle of Man, Russian Federation, Slovakia and Ukraine. Comparative analyses of antenatal and postnatal data were now feasible.

ELSPAC PROTOCOL

Participants updated the ELSPAC Survey Development & Protocol in the light of developments within countries, to create a fourth edition.

QUESTIONNAIRES AT 7 YEARS

The meeting spent two days deciding on an outline of the information to be put into the questionnaires to be administered at 7 years, with three aims in mind: first, to repeat various items over the long term; second, to ensure that new questions were identified that were appropriate at this stage in the child's life; and third, to ensure that questions of importance to future development into adulthood be asked. It was agreed that there should be a questionnaire for the teacher and another for the child, as well as the three (mother, father, child) to be administered as usual.

The questionnaires for mother, father and child should be sent to the study coordinators as soon as possible after the meeting so that translation and back-translation could proceed rapidly.

ASSESSMENTS AT 7 YEARS

The initial aim of the ELSPAC study had been to look at the way in which early events and environmental factors influenced the development of the child as measured at 7 years. The oldest study children would be 7 in 1998, so planning and piloting were urgent and important.

A certain number of mandatory assessments should be carried out on the children in each country, together with a set of optional items. These assessments should be carried out in exactly the same way in all study centres using, where appropriate, the same equipment, and all observers should be trained in exactly the same way. The meeting discussed the items.

Mandatory assessments

Items considered as mandatory are outlined below and listed in detail in Annex 2.

- *Growth* – height, weight and head circumference, measures such as abdominal circumference, mid-arm circumference, and sitting height (optional). Skin-fold thickness measurements, since other studies have shown reliability between observers.
- *Blood pressure* – to be measured using the same equipment in each country.

- *Vision* – standard measures of visual acuity and assessment of squint.
- *Colour blindness* – standard tests.
- *Dental observations* – caries, erosion, mottling.
- *Hearing* – standard audiometry tests.
- *Lung function* – a two-minute spirometry test, using the same standard equipment, to measure the lung function of the child (size of lung and air flow before and after metacholine challenge).
- *Motor coordination* – standard tests for motor coordination, using tests of gross motor and fine motor competence, in order to identify children with motor impairments.
- *Speech tests* – speech tests specific to the countries and languages involved (it is anticipated that there are totally different problems in different countries).
- *Cognitive function* – IQ tests on all children: since this is a lengthy procedure which has to be done on a one-to-one basis, each country should determine whether there are reliable tests available which would give verbal and non-verbal components of the IQ.

Optional items

A number of other assessments were suggested (Annex 2).

Practical arrangements

By streamlining the assessments considered mandatory it should be possible to carry them all out within 2½–3 hours. Testing could take place at any time between the 7th and 8th birthdays.

The study group felt that although the science behind the plans was good, the costs involved were daunting. Sue Sadler pointed out that, with the exception of the dental examinations, there was no need for medical practitioners or clinical psychologists to carry out the examinations. In western Europe this would be considered a financial saving; in the Russian Federation and Ukraine, however, paediatricians were likely to be the cheapest source of examiner, but some of the tests fell within the educational rather than medical fields. In addition, physicians would not be familiar with psychosocial tests.

Participants agreed that relevant experts in each country should be invited to collaborate in order to ensure the best expertise available to help decide on appropriate cognitive and speech tests and ensure the training and validation of the observers. In addition, they should be encouraged to apply for funding for various aspects of the study and possibly encourage postgraduates to use the data collection and analysis as part of a postgraduate degree.

Timing

Ideally, the study sample to be tested at 7 should consist of all those who were eligible at the time of birth. Recent immigrants could also be included.

The different cohorts would reach the age of 7 at different time points. It was not, however, necessary to do the study when the child was exactly 7. Indeed, it might be more advantageous to wait. Current plans are for the following start dates:

Isle of Man	March 1998 or later
Czech Republic	March 1998 or later – in Brno, but possibly not Znojmo
Avon	August 1998
Russian Federation	January 1999
Slovakia	September 2000
Ukraine	September 2000

The Czech Republic, Russian Federation, Slovakia and Ukraine would do their own versions of the health report, taking advantage of their own systems. It was possible that this would be based on a study of child development and psychological and motor development carried out Professor Ignatyeva in Lipetsk. They would arrange to meet in Brno.

It would be helpful if Professor Golding could write an official letter of support to each country for this meeting. The meeting could also be used by Dr Kukla and Professor Valky to progress the two volumes of the obstetric and neonatal book.

Inclusion criteria

In the Russian Federation the study will include all eligible children (based on date of birth) regardless of whether or not they were in the original cohort. It will thus include newcomers to the area. There are many immigrants from the Caucasus who would form an interesting comparison group. It is aimed to establish warm relationships with the teachers of all the children of the right age in the hope that they will fill in the teacher questionnaire on each child in their class that is eligible for the study and voluntarily carry out tasks such as the distribution of questionnaires.

In the Czech Republic the study would cover all eligible children but not necessarily include immigrants. There is a stable gypsy population which has problems with literacy. These have dropped out of the original cohort, but may be included at 7.

In the Isle of Man all children born in the appropriate time period will be included (hence all immigrants to the island will be covered). There is a new director of primary school education and the organizers are hoping to raise his awareness of the study.

In Ukraine, it was thought that all children in the same class would be included with a comparison of those who were originally in the study and those who were not.

Slovakia does not have an immigrant problem and was thought to be including only the original eligible children.

It would be a different problem to identify children who were severely disabled and either in special homes or at home and not at school. This must be considered as they are a most important outcome group. In the Russian Federation, there might be a problem with children attending private schools, especially those in schools run by the many different religious sects. This would have to be tackled separately.

PUBLICATIONS AND AUTHORSHIP

Publications

Each country provided a list of all publications and presentations. These have been included in the fourth edition of the ELSPAC Protocol.

The first ELSPAC book – *Pregnancy in the nineties* – had been published in September 1996 and had been well received in each of the study countries.

Authorship

No further debate occurred in this meeting concerning the way in which appropriate authors were agreed for collaborative publications after the exhaustive debates the previous year. The current recommendations were that:

(a) publications in the international peer review press were important for raising funds for the ELSPAC study in each country;

(b) since the study directors had devoted an enormous amount of work to data collection but had little time themselves to write up the results, experts in different fields should be encouraged to analyse and write up the data.

* For collaborative papers with no assistance from outside the ELSPAC teams, one name only from each country study should be included in the list of authors – that name to be decided by the director in each country. The authors should be listed in the order of the greatest amount of effort in writing and rewriting the paper.

* In the case of papers written by persons outside the immediate study teams, the authors' names should be put first on the paper together with representative names from each country (as detailed above).

Rules for comparative analyses

The procedure for comparative publications is as follows:

(a) A one or two page outline of the study should be submitted to Jean Golding, who will fax it to members of the CEC for outline approval.

(b) If the CEC approves, the scientist concerned should get approval directly from the study director of each country being compared.

(c) When those study directors willing to cooperate give their approval, the scientist should approach Hugh Simmons with a request for the data.

Once the paper is written, it will be sent to the study directors in each of the countries used for (a) comments and alterations and (b) identification of the named author from each country.

On publication the first author should send each other author and each member of the CEC two copies of the paper.

Planned ELSPAC books

Three books are currently planned, as outlined below.

I. European Longitudinal Study of Pregnancy and Childhood (ELSPAC): methodology and study participants

This will provide essential reading for anyone working on ELSPAC data now and in the future. It will be edited by the CEC, who will co-opt authors to contribute as necessary. Professor Ignatyeva proposed the following contents.

Chapters 1–8
These will be the same as in the protocol, although Professor Shkiriak-Nyzhnyk had offered to submit the text of a methodology paper that she and Susan Monoghan had written.

Chapter 9. External environment at the study sites
Dr Kagramanov had distributed an outline in November and had received data as requested from Slovakia and from his own study in the Russian Federation. The Czech Republic was in the process of responding; Greece had asked an environmental epidemiologist to help; the Isle of Man had already sent in their report, and the data from the County of Avon had been prepared by Alex Farrow. The Ukrainian sub-chapter was with Susan Monaghan in the USA.

In future, the papers and diskettes that had not yet been submitted should be sent directly to Professor Golding, who will copy them to Professor Ignatyeva. It was agreed that the authors of each outline sent to Dr Kagramanov should be authors of the whole chapter.

9.1 The Czech Republic
9.2 Greece
9.3 Isle of Man
9.4 The Russian Federation
9.5 Slovakia
9.6 Ukraine
9.7 United Kingdom – County of Avon
9.8 Conclusion

Chapter 10. Comparative analysis of the demographic situation in participating countries (1970–1994)
This chapter is being written by Professor Ignatyeva who has agreed to omit sections on marriage rate and divorce rate trends as well as reproduction rate trends. The Health for All data base should be used and the data for each country sent to that country to see if it was satisfied with the information. For clarity, graphs should be in colour, but this had major costing implications. Dr Kukla was hoping to prepare his own data as he did not think WHO's data were sufficiently accurate for his country. The Ukrainian government has requested that their own demographic data should be prepared as it was a sensitive subject. The Minister of Health wished to receive a copy before the chapter is finalized. Generally, perinatal and other mortality data will be difficult to portray accurately because of varying definitions, and a descriptive analysis only may be used in some areas.

10.1 Birth rate trends (including age-related and fertility trends)
10.2 Mortality trends
10.3 Natural growth (decrease) trends
10.4 Infant mortality trends
10.5 Perinatal mortality trends
10.6 Childhood mortality trends
10.7 Maternal mortality trends
10.8 Induced abortion rate trends
10.9 Use of contraceptive trends
10.10 Life expectancy at birth trends
10.11 Conclusion

Chapter 11. Organization and distribution of health services with particular reference to maternal and child health care (1990–1995)
Oleysha Hulchiy had kindly offered to produce this chapter.

11.1 The Czech Republic
11.2 Greece
11.3 Isle of Man
11.4 The Russian Federation
11.5 Slovakia
11.6 Ukraine
11.7 United Kingdom – County of Avon
11.8 Conclusion

Chapter 12. Acknowledgements (including funders)

Chapter 13. Literature cited

Chapter 14. Publications up to 1.1.97

14.1 Papers in peer-reviewed journals
14.2 Articles in other journals
14.3 Books
14.4 Unpublished reports
14.5 Conference presentations
14.6 Theses and dissertations

II. Giving birth in the nineties

This book will be designed in a similar way to *Pregnancy in the nineties*. It will be written by Stephanie Goodfellow, Ilona Koupilova and Thalia Dragonas, and will use data from the antenatal, delivery and 6-week questionnaires. The proposed structure of the book is as follows:

I. Attitudes and expectations
1. Reactions to becoming a parent
2. Expectations of labour
3. Components of antenatal care

II. Labour
4. Circumstances surrounding delivery (including social support)
5. The partners' reactions to labour and delivery

III. The post-partum period

6. Social and domestic circumstances
7. Infant care
8. Emotional wellbeing of mother and partner
9. Maternal morbidity
10. Paternal morbidity
11. Coping at home
12. Breastfeeding (including time to first feed) and early attachment.

N.B. Analysis of these attitudes, expectations and experiences will compare primiparae and multiparae. It was also thought that comparison of data by maternal education level and age might be useful, and participants agreed that as far as possible longitudinal analyses could be carried out.

III. Delivering a baby in the nineties

This will be devoted to the medical aspects of pregnancy, labour, delivery and the neonatal period. It will mainly use data from the delivery, neonatal admissions and death questionnaires.

Dr Kukla will coordinate and edit the book in association with Professor Války and Dr Valkyova (for obstetric advice), and Dr Kagramanov who will analyse data on deaths and neonatal admissions.

After considerable discussion, participants concluded that the amount of data was probably excessive for one volume and it was likely that the book would be prepared in two volumes. The chapter headings would be as follows:

1. Complications of late pregnancy
2. Problems with labour and delivery
3. Mode and circumstances of delivery
4. Third phase of delivery and problems
5. Mortality (fetal and neonatal)
6. Birthweight, birth length, gestation
7. Apgar and other signs of birth asphyxia and trauma
8. Multiple pregnancies
9. Neonatal admissions
10. Morbidity of the young infant.

Dr Valkyova said that it would be important to include consideration of preterm deliveries and eclampsia. It was suggested that funding for this book might be sought from Soros International (New York) or the Carnegie Foundation. Dr Kagramanov (currently working in the USA) might be able to make preliminary approaches but would need letters of introduction.

REPORT FROM THE COORDINATING AND EXECUTIVE COMMITTEE

Unfortunately, two of the four members of the 1996 Coordinating and Executive Committee (CEC) were unable to attend. Consequently, Professor Golding was only able to discuss the situation with Professor Ignatyeva and, by telephone, with Professor Dragonas who was unable to attend. Participants decided unanimously in favour of co-opting Dr Kukla as a permanent member of the CEC.

Contributions to the funding of the Coordinating Centre were discussed. The 1995 meeting had agreed a fee of £4000 per centre per year. For 1997 this had been achieved for the Russian Federation (from an American grant).

This made it extremely difficult for the Bristol office to provide an adequate service. It had been suggested and agreed in 1996 that future grants from national and international funders should include a 10% fee to be given directly to Bristol, and all participants were encouraged to remember this.

Confidentiality was stressed. The study rules must be such that no-one can link the name of a parent or child to the information given in the self-completion questionnaires.

OTHER MATTERS

The meeting had included a statistical workshop. This had been very successful and Dr Koupilova was warmly thanked. Participants agreed that it would be useful to repeat the exercise in the future.

There was general agreement that the policy should be to continue the study beyond 7 years of age, and indeed to follow the children into adulthood if possible.

Professor Golding reported on a meeting which had been held in London on 25 November 1996. This had been a high profile affair to which a number of United Kingdom government ministries, research councils, medical charities and heads of research in industry had been invited with the aim of raising the profile of the Avon study, inviting cooperation, collaboration and funds. It had been agreed that the ambassadors from each of the collaborating ELSPAC countries should be invited and that the relevant British Embassy in each country be informed. In the event, Minister-Counsellor Milan Jakobec of the Czech Embassy had attended.

THE 1998 MEETING

Participants agreed to ask WHO to continue to fund meetings of collaborators, and suggested that the next meeting be in September in Bristol.

Annex 1

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Annex 2

THE PROPOSED 7-YEAR TESTS

1. Vision

a. Mandatory

Obtain visual acuity (using a LogMar or Snellen Chart) in each eye of all children, at 6m in standardized conditions, with their glasses if they wear any. This could be done by an orthoptist or a suitably trained non-specialist. Children with poor vision in one or both eyes would need to be checked by a specialist later to classify the cause of their reduced vision, e.g. amblyopia, uncorrected refractive error or other pathology, such as optic nerve defects.

As well as vision in each eye, a cover test would be performed to examine the alignment of the eyes and diagnose squint if present. This would ideally be done by an orthoptist or similar specialist. Eye movements in all directions and prism tests (to look for the ability to fuse two images into one) could also be carried out quickly by an orthoptist.

b. Optional

Stereopsis (depth perception) can also be tested simply by trained non-specialists as can contrast sensitivity (using a Pelli Robson chart), and both would give further useful information about whether vision had developed normally in each child.

If funding is available, an autorefractor would be used to obtain measures of the child's refractive error. This would back up the above findings and would also identify extra children with good vision who are constantly having to 'strain' as a result of extreme long-sightedness. Other tests will include looking for suppression of either eye, which is another sign of abnormal interactions between the eyes.

2. Dental observations (mandatory)

General dental development and oral and dental disease will be assessed by trained dental staff. Observations will be recorded in coded form on to audiotape and transcribed later.

3. Blood pressure (mandatory)

The children's blood pressure will be taken using a Dinamap 9301 vital signs monitor. Staff will aim for two readings with the child sitting quietly with arm at chest height. Pulse rate, room temperature, and the demeanour of the child will be recorded. This will be repeated after exercise.

4. Lung Function (mandatory)

Lung function will be measured using a Fleisch electronic spirometer connected to a computer-based pulmonary function package (Spirotrac III, Vitalgraph, UK). An incentive-based system in the package will be used for all children, and American Thoracic Society guidelines[1] will be used to assess the acceptability and reproducibility of the test results.

A nose-clip will be applied and children will be instructed to blow through a mouthpiece. An on-screen incentive will be used to encourage maximum effort. Testers will be instructed in fundamental

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[1] Crapo, R.O. et al. Standardization of spirometry, 1994 update. *American journal of respiratory and critical care medicine*, **152**: 1107–1136 (1995).

quality control criteria to ensure adequate reproducibility of results. Five forced expiratory manoeuvres which fulfil these criteria will be measured and the data stored for each child. The flow-volume curves thus generated will be inspected later to ensure that they meet acceptibility criteria. The following measurements will then be recorded: peak expiratory flow (PEF), forced expiratory volume in 1 second ($FEV_{1.0}$), slow vital capacity (SVC) and forced vital capacity (FVC) and maximal flow at 25%, 50% and 75% of forced vital capacity ($V_{max}25$, $V_{max}50$, $V_{max}75$). These data will be saved as absolute values and as percentages predicted for the child's height.

5. **Allergy tests** (optional)

Skin prick tests for 12 common allergens will be administered and read 10–15 minutes later.

6. **Anthropometric measures** (mandatory)

Standing height will be measured, together with weight and arm, waist, hip and head circumference. Skinfold thickness measurements will be included. Optional: flat feet and sitting height.

7. **Skin observations**

- Presence, nature and severity of any skin lesions, including eczema and melanocytic naevi (mandatory)
- Skin colour of inner surface of the arm using a reflectance spectrophotometer (optional)
- Hair colour using 'wig makers' samples (optional)
- Eye colour (measured by reference to 6 photographs of 6 irises, and noting presence of differently coloured colorette, brown patches and naevi) (optional)
- Examination of child's hair and nails, with investigation of any abnormalities (optional).

8. **Physical fitness** (optional) **and Motor coordination** (mandatory)

Tests of physical fitness will be based on the Eurofit battery and will include cardiorespiratory fitness, percentage body fat, strength and flexibility, and also basic motor skills. Fine and gross motor coordination will be carried out using standardized tests.

9. **Biological samples** (optional)

Where permission is given by parent and child a venous blood sample will be taken using the Sarstedt monovette system. The vein will first be identified and covered with EMLA cream (a local anaesthetic) for at least 50 minutes before the sample is taken.

The blood will be spun down, aliquoted and stored. There are plans for genetic analysis using the DNA, of whole blood assays for haemoglobin and lead, for red cell assays to assess the essential fatty acids and for serum assays of IgE, cholesterol, ferritin and antibodies to a variety of infections.

Other samples such as urine and buccal smears are under discussion.

10. **Hearing** (mandatory)

Closed field pure tone audiometry will be used in good stable acoustic conditions to screen the children's hearing at $500H_z$, $1000H_z$, $2000H_z$ and $4000H_z$ in each ear separately with a Kamplex AD12. The screening level will be 20dBHL. Any child who does not hear at this level will be referred for a full pure tone audiogram and a tympanogram by a qualified audiologist as soon as possible after this visit.

Tympanometry will be carried out with a Kamplex AT2 tympanometer to measure middle ear function.

11. Intellectual development (mandatory)

A culture-specific standard intelligence test, probably the WISC (or the local equivalent), will be used. This should provide an assessment of verbal and non-verbal IQ.

12. Speech and language (optional)

There will be a culture-specific test for speech sound difficulties, and expressive language.

13. Short-term memory test (optional)

Tests of verbal and visual-spatial short-term memory will be given. These tests will include the corsi-blocks test.

14. Possible testing for parents (optional)

The feasibility of obtaining proxies for parental non-verbal and verbal IQ is being investigated. Ravens' matrices and the Spot-the-Word test will be pilot tested with a variety of adults of different social and educational backgrounds.

In addition, it may be possible to weigh and measure the parents, take blood pressure and measure lung function, as well as taking a buccal smear for DNA.