# Oregon Health Authority
# Northwest Regional Newborn Bloodspot Screening Advisory Board
# FUNDING SUBCOMMITTEE

## Meeting Summary September 21, 2022

**Location**
Videoconference

**Subcommittee Members Attending**
Marilyn Hartzell, M.Ed., (advisory board chair) Person or family member of a person affected by a disorder on the newborn screening panel
Andrea Keating, LDM, CPM, Representative of a statewide association of midwives
Dawn Mautner, MD, MS, Representative of Medicaid or insurance industry
Joanne Rogovoy, Advocacy association regarding newborns with medical or rare disorders
Kara Stirling, MD, Representative of a birthing center or hospital
Amy Yang, MD, Contracted medical consultant

**Subcommittee Members Absent**
Wannasiri (Awe) Lapcharoensap, MD, Representative of a statewide association of pediatricians

**Program Staff**
Oregon Health Authority:
- Sheri Hearn
- Patrice Held (advisory board chair)

**Guests**
Cate Wilcox

**Members of the Public**
Ellie Bogs
John Powell
Mary Buko (Oregon Consensus student observer)

**Oregon Consensus Facilitation Team**
Robin Harkless, facilitator
Cat McGinnis, project associate

**ACTION ITEMS**

- Andrea will reach out to the Oregon Midwifery Council and report to the subcommittee about providers' current experiences and needs.
- Patrice will report on the following at the Nov subcommittee meeting:
    - Foundations that might develop an equity fund, especially for self-payers. (Will also ask whether general funds could be funneled into such a pot of money.)
    - More info on WA funding for newborn screening
    - If possible, map out anticipated increases in financial needs.
- Patrice shared data in her slides about the number of infants covered by medicaid and number of infants covered by high-deductible insurance plans or community insurers. More data points may need to be gathered to complete the picture. For example, how much would it cost to provide screening cards to midwives in advance at no cost?
- Next subcommittee meeting confirmed: November 9, 2022, 9-11am PST over zoom.

**MEETING AGENDA ITEMS**

1. **Public health models for funding the NWRNBS program and screening costs not covered by insurance—Cate Wilcox**
    - The key is to keep the financial burden off families.
    - As preventive medicine expands, it is difficult for insurers, who are used to CPT codes. Insurers want to see a return on investment in insureds within the first year of coverage.
    - Possible funding sources:
        - The WA Legislature set up the Home Visiting Service Account to cover at-home child preventive health services that are not covered by insurance. More on WA program: https://www.dcyf.wa.gov/services/child-dev-support-providers/home-visiting/hvsa. We need to look more at this approach. Foundations and legislature could put money into such a fund. When/if the time comes to bring this concept to the legislature, Rep. Reynolds and Senator Hayward would be good people to approach.
        - It would be worth pursuing working with community health plans. It would be a lengthy process unless the legislature expanded coverage.
        - The tobacco master settlement fund and the opiate master settlement fund brought a lot of money into the state. Might be helpful to have them speak to the subcommittee but would need to find a connection with NWRNBS issues.
        - Could have a fund for infants who are on high deductible plans. Of the 40,000 births in Oregon annually, 1,200 are infants on these plans.
        - Perhaps champions could approach DHS to have screening covered as preventive medicine, such as well-child visits, which have to be paid for by the insurer before the deductible.
        - Infants are considered the Medicaid client. In most states, half of births are covered by Medicaid.
        - Oregon data to collect: number of infants covered by medicaid and number of infants covered by high-deductible insurance plans or community insurers. Need to take this number (and dollar amount) to the legislature and have them set up

a fund for these infants. Also need to address midwifes—how much would it cost to provide screening cards to these practitioners in advance at no cost?
    - Is there a way to move away from a fee-for-services model for screening?

**2. Funding models in other states—Patrice Held (See appendix A for presentation slides)**

- Data is from Association of Public Health Labs from June 2020.
- States have a range of fees for screening because some use couriers, some do one screen and others two, some include hearing and heart screening, some screen more disorders than others, some use private labs, and some pay higher staff salaries than others.
- Most state programs are funded by fees for services, others by general funds or maternal-child health grant (Title V). Others have a mix of funding sources. (See appendix A for full data.) Note: Per Kate, Title V funds in Oregon are already spoken for.
- State approaches for collecting fees vary. Some use indirect funding by pre-selling screening cards to providers (Oregon does this). Other programs direct bill the hospital, insurance or medicaid after screening. Oregon would face hurdles if it moved to direct billing—need more staff, need to deal with denials and resubmissions, insurance companies need specific info not currently required, need to negotiate contracts with insurers. Oregon is not capable of doing direct billing currently.
- Fees are held in different places in different states. Some fees go to a pot for the state's program to use at its discretion. Some states' fees go into the general fund.
- Patrice spoke with WA about their approach. They direct bill hospitals and direct bill insurance for midwives. Problems they encounter: hospital often delay payment, sometimes insurer doesn't cover full fee.
- One subcommittee member felt that insurers should deal with costs not covered and pay for cards and lab work, but should not be responsible for costs of running a lab. Patrice point out that the OR fee is also covering couriers, education, and more.
- Robin summarized the discussion so far and noted two parallel discussions happening:
    - Who is paying for—and who should be paying for—screening?
    - How will the program holistically support itself over time? (This is broader than how the fee is charged and where it is held.) Potential data needed for this discussion: Can the program lay out the arc of future financial needs?
- A subcommittee member pointed out: in Oregon, hospitals are bundling the bill for the whole birth and insurers are paying. However, about 2,000 community births are not covered. How can Oregon cover those better? Suggests the lab should be free to adjust the fee to address the needs of the lab, but needs to find a way to support the 2,000 births.
- <u>Action:</u> Andrea will reach out to the Oregon Midwifery Council and report to the subcommittee about providers' current experiences and needs.

3. **Next steps/actions**
    - Subcommittee will meet in November to prepare information for the full advisory board meeting in December. (Cat, Oregon Consensus, sent out a Doodle poll and confirmed the meeting date: **November 9th, 9-11am PST over zoom**.)
    - Patrice will report on the following at the Nov subcommittee meeting:
        - Foundations that might develop an equity fund, especially for self-payers. (Will also ask whether general funds could be funneled into such a pot of money.)
        - More information on WA funding for newborn screening
        - More information about the flow of revenue/funds from the newborn screening fees. How much goes directly to the Program? Gets absorbed in General funds? Or elsewhere?
        - If possible, map out anticipated increases in financial needs.
    - Andrea will talk with the Oregon Midwifery Council about their needs and report at the Nov subcommittee meeting.
    - A request was made to look at March of Dimes or other organizations to expand ideas about funding models.

**Adjourned**

**Appendix A: Presentation on other states' NBS program funding models—Patrice Held**

# Northwest Regional Newborn Bloodspot Screening Program Advisory Board

Subcommittee on
Long-Term Program Funding
September 21, 2022

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**2020 Maternal Demographics** (Center for Health Statistics)

| | % of births (n=40,185) | Medicaid/OHP | Private Insurance | Self-Pay | Other Coverage |
|---|---|---|---|---|---|
| Planned hospital births | 95.5% (n=38,371) | 43.5% (n=16,687) | 54.5% (n=20,926) | 0.7% (n=277) | 1.3% (n=481) |
| Planned out-of-hospital births (e.g., birth centers, home births) | 4.5% (n=1,814) | 24.5% (n=444) | 43.7% (n=792) | 31.2% (n=566) | 0.7% (n=12) |

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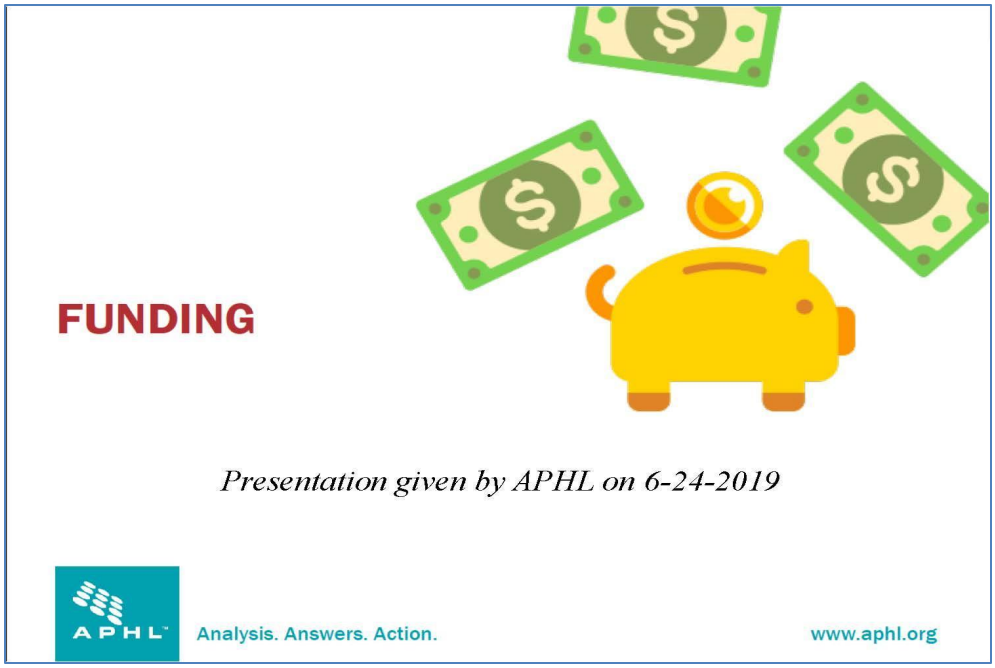
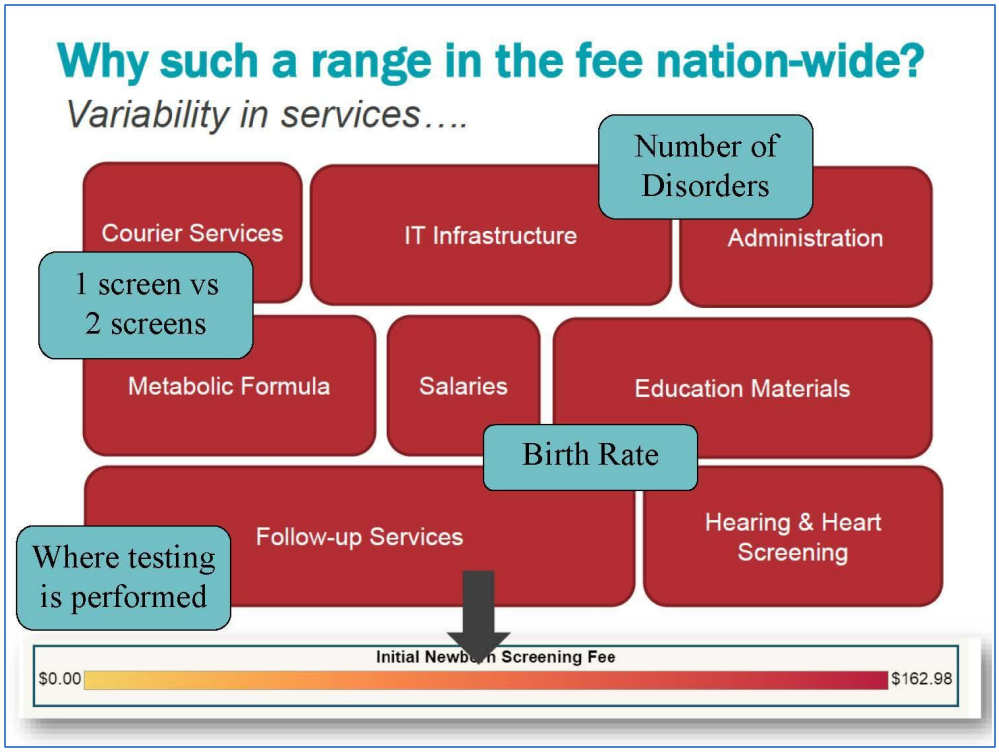
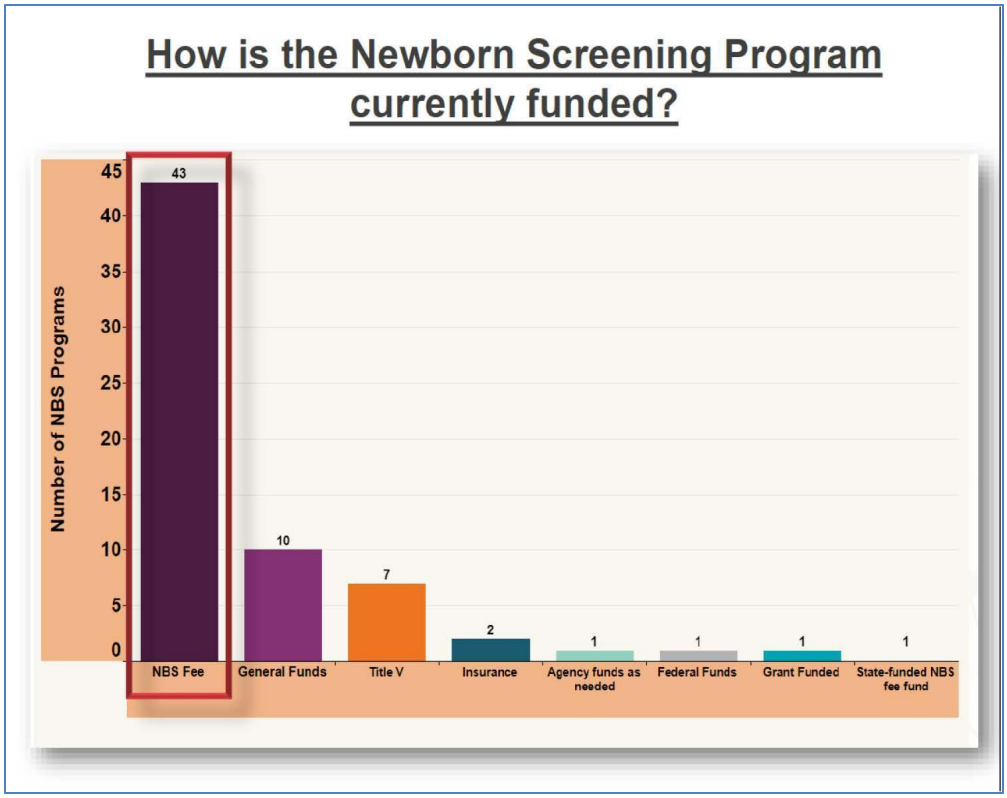
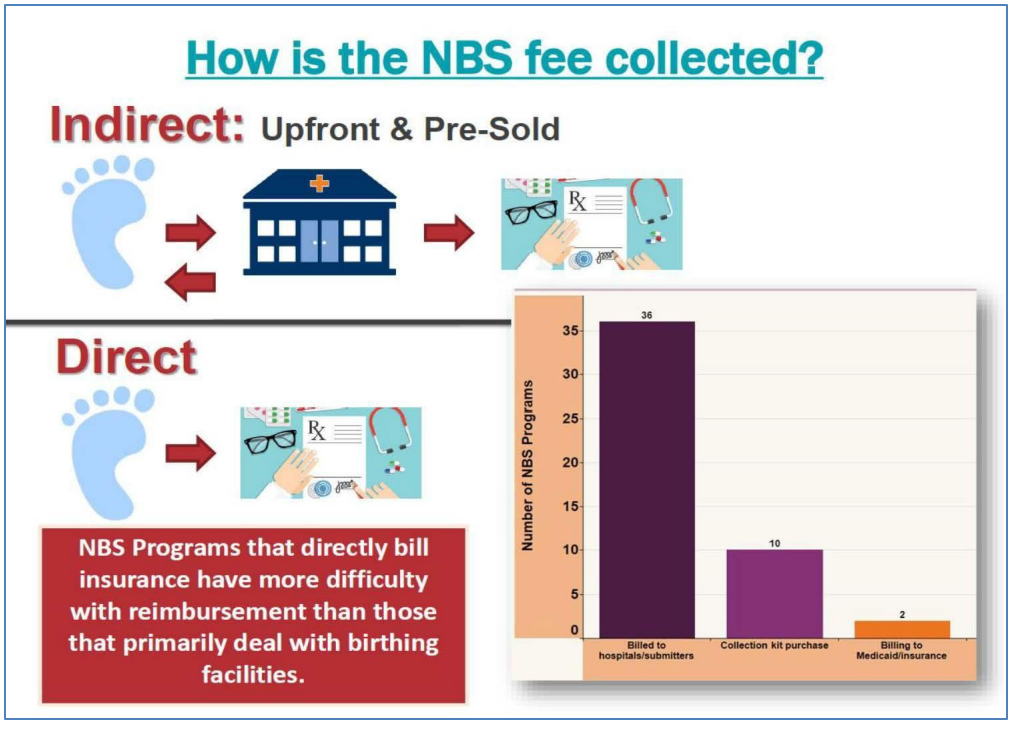
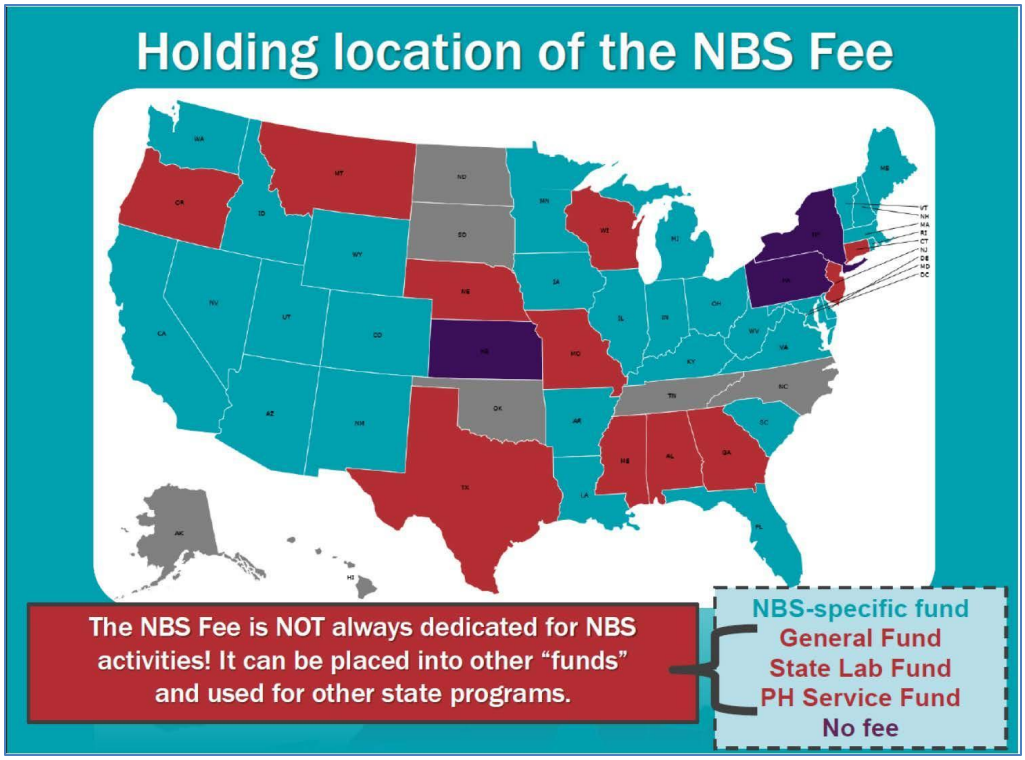
2

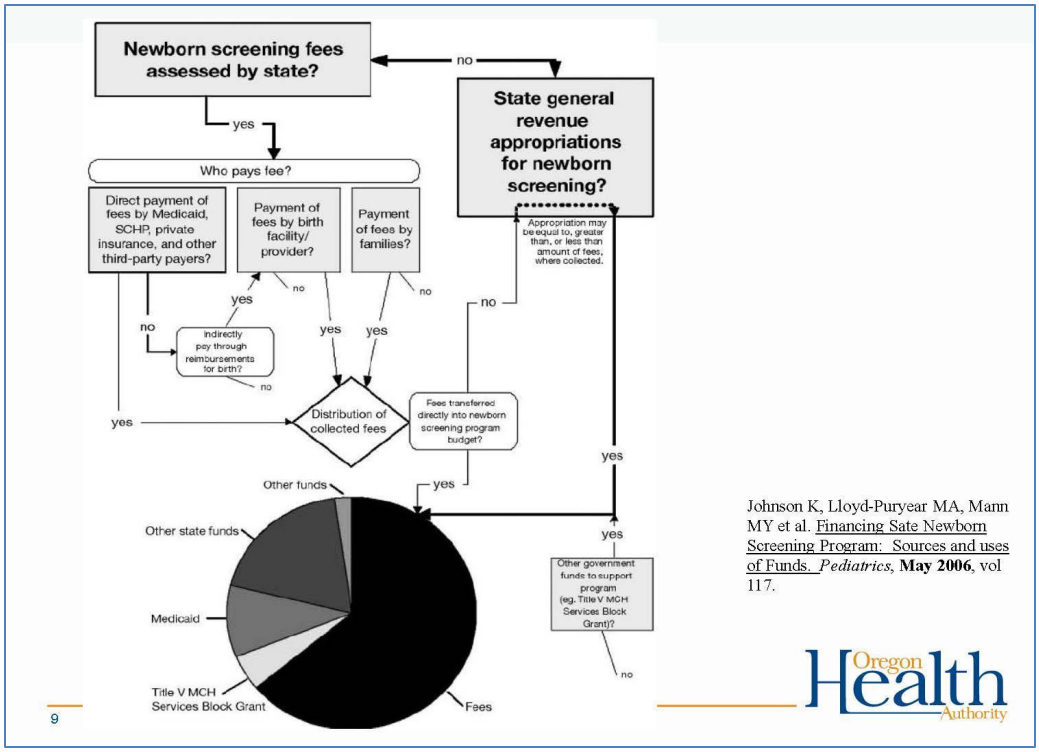

FUNDING
Presentation given by APHL on 6-24-2019
APHL
Analysis. Answers. Action.
www.aphl.org


Why such a range in the fee nation-wide?
Variability in services….
Number of Disorders
Courier Services
IT Infrastructure
Administration
1 screen vs 2 screens
Metabolic Formula
Salaries
Education Materials
Birth Rate
Follow-up Services
Hearing & Heart Screening
Where testing is performed
Initial Newborn Screening Fee
$0.00
$162.98


How is the Newborn Screening Program currently funded?
Number of NBS Programs
45
40
35
30
25
20
15
10
5
0
43
10
7
2
1
1
1
1
NBS Fee
General Funds
Title V
Insurance
Agency funds as needed
Federal Funds
Grant Funded
State-funded NBS fee fund


How is the NBS fee collected?
Indirect: Upfront & Pre-Sold
Direct
NBS Programs that directly bill insurance have more difficulty with reimbursement than those that primarily deal with birthing facilities.
Number of NBS Programs
36
10
2
Billed to hospitals/submitters
Collection kit purchase
Billing to Medicaid/insurance


Holding location of the NBS Fee
The NBS Fee is NOT always dedicated for NBS activities! It can be placed into other "funds" and used for other state programs.
NBS-specific fund
General Fund
State Lab Fund
PH Service Fund
No fee


Newborn screening fees assessed by state?
no
State general revenue appropriations for newborn screening?
yes
Who pays fee?
Direct payment of fees by Medicaid, SCHP, private insurance, and other third-party payers?
Payment of fees by birth facility/ provider?
Payment of fees by families?
Appropriation may be equal to, greater than, or less than amount of fees, where collected.
Indirectly pay through reimbursements for birth?
Distribution of collected fees
Fees transferred directly into newborn screening program budget?
Other funds
Other state funds
Medicaid
Title V MCH Services Block Grant
Fees
Other government funds to support program (eg, Title V MCH Services Block Grant)?
Johnson K, Lloyd-Puryear MA, Mann MY et al. Financing Sate Newborn Screening Program: Sources and uses of Funds. Pediatrics, May 2006, vol 117.
9
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## Active State Leaders in Policy Reforms

*potential partners*

- **Public health department staff members**
  - NBS program director and/or director of health
- **Genetic or NBS advisory groups**
- **Governor and/or legislature**
- **Advocates**
  - Parent groups, March of Dimes, Disease-specific organizations, Celebrities with affected children

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10

## References


- Johnson K, Lloyd-Puryear MA, Mann MY et al. Financing Sate Newborn Screening Program: Sources and uses of Funds. *Pediatrics*, **May 2006**, vol 117.
- Therrell BL, Williams D, Johnson K et al. Financing Newborn Screening: Sources, Issues, and Future Considerations. *J Public Health Management Practice*, **2007**, vol 13(2).


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11